THE SOCIAL ASSISTANCE NEEDS OF CHILDREN WITH CHRONIC HEALTH CONDITIONS:

THE APPLICATION AND COMPARISON OF TWO INTERNATIONAL INSTRUMENTS IN THE SOUTH AFRICAN CONTEXT

By

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Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signed by candidate

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ABSTRACT

Children with chronic health conditions in South Africa are a vulnerable group of children, whose additional needs resulting from their condition places financial strain on their caregivers and families. Poverty plays a significant role, and often exacerbates the situation for these children and their caregivers. They are a group of children who require additional assistance from the State – social assistance (a term used for financial aid in South Africa) is one form of support that can be extended to these children. The present social assistance provisioning for these children is limited, and assessment processes and instruments are unsatisfactory.

This study is an examination of the application of international social assistance assessment instruments to the South African context, namely the Australian Child Disability Assessment Tool and the United Kingdom's Disability Living Allowance Claim Form. The study purposed to make recommendations for the development of an appropriate South African social assistance assessment instrument. Secondly, it aimed to demonstrate through the application of these international tools that there are areas of need related to chronic health conditions that are presently not provided for by the current South African social assistance programme. The study design assumed the form of a descriptive, comparative study of existing international instruments. Non-probability sampling was employed, and the findings of the study are analysed via a combination of quantitative and qualitative data analysis.

A small sample of 18 children from the Western Cape was selected, representing 6 types of chronic health conditions, specifically disability and chronic illnesses. The caregivers of the children were interviewed on two occasions, for the administration of the two international instruments. An additional question was asked of the caregivers in relation to their concerns and problems that the two instruments did not identify. The data was analysed in relation to the needs identified by the caregivers, and the children were assessed for eligibility to the United Kingdom and Australia's social assistance benefits. Their eligibility for the South African social assistance benefit was also assessed. Data collected from this process was analysed to identify commonalities and differences between the three instruments. Both international instruments were evaluated for its advantages and disadvantages as assessment instruments, and it's applicability to the South African context.

Key findings indicated that the children had a vast array of needs resulting from their chronic health conditions. These included health care needs, educational needs, and needs related to activities for daily living. Primarily, these children required care, supervision and assistance to accomplish daily life activities and to maintain their health. The carers of the children indicated that they faced adverse circumstances, the majority of whom were living in poverty, and providing care for a child who required extra care and attention on a daily basis. Factors that influenced their ability to care for their children optimally were lack of finances, difficulties surrounding travelling to health care facilities, and a lack of support structures, as well as the emotional impact of providing care. These carers also encountered direct risks and losses as a result of providing care for these children.

Findings also revealed that the majority (56%) of the sample was not eligible for the South African grant based on the current system. In contrast, the large majority of the sample was eligible for the United Kingdom's benefit (94%), and for the Australian benefit (89%). Significantly, the majority of the children that were excluded based on the South African system were children with chronic illnesses.

The United Kingdom's tool was found to predominantly capture the needs of children with chronic health conditions, mainly through qualitative information. However, the tool is impractical because of its length, inappropriate questions and cumbersome structure. Conversely, the Australian tool is a functional assessment, but it was also found to capture the children with significant needs. The instrument is easy to use, and the scoring process is fairly simple.

Recommendations that were made proposes that the scope of the South African grant be re-evaluated to consider children with chronic illnesses and other vulnerable groups. In addition, a holistic approach to the assessment process and assessment instrument should be considered. It was also recommended that a simple and user-friendly mechanism for determining eligibility be developed. Finally, it was recommended that a phased-in approach to the inclusion of a range of needs and conditions for social assistance be considered in light of South Africa's fiscal limitations.

CHAPTER 1: INTRODUCTION

The following chapter presents the motivation for this study, followed by an explanation of the derivation of the research topic and the research problem. Hereafter, the research design and methodology is introduced and the remainder of the thesis briefly described.

MOTIVATION FOR THE STUDY

Social security in South Africa is currently undergoing large-scale revision with the aim of developing a more comprehensive social security system (Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, 2002). A primary rationale for this revision is the unsatisfactory and limited processes of assessment for determining eligibility to social assistance, a form of social security, which plagues the present South African system. Other processes are also underway to reform the social assistance programme, particularly for children with disabilities.

The Social Assistance Grant for Children With Disabilities

The Care Dependency Grant is a financial grant of R630 per month, awarded to caregivers of children with severe disabilities as part of the present social assistance system. The grant is intended to assist caregivers whose child can only be cared for at home. This results in the carer having to remain at home to care for the child or employing a substitute carer (Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, 2002). The grant was implemented during a period in South Africa when little other care options were available to caregivers. A child is eligible for this benefit if he or she is aged between 1 and 18 years and requires permanent home care as a result of a severe physical or intellectual disability (National Consultative Workshop Report, 2001). Additionally, a means-test is applied to the grant applications, and consequently only caregivers receiving an income below the R48 000 per annum threshold are eligible for the benefit.

The Assessment Process

Presently, a medical doctor, employed in a government hospital, assesses the child to determine severe physical or intellectual disability and verifies that the child is in need of care and that the parents of the child are able to adequately care for the child at home. Applications are made through the local welfare offices (Guthrie & Sait, 2001), and the Pension Officer makes the final decision regarding the approval of the application.

However, this system is fraught with many inconsistencies. These inconsistencies and limitations stem from the fact that The Care Dependency Grant is limited in its scope and purpose, and lacks clear eligibility criteria and clearly defined terms. For example, terms such as 'severe disability' or 'permanent home care' are not adequately defined in the Social Assistance Act, 1992 (Act 59 of 1992) (Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, 2002). Additionally, children with either moderate disabilities or chronic illnesses cannot access the grant, as the grant targets only children with severe disabilities requiring permanent home care (National Consultative Workshop Report, 2001). The current definition of disability is also based solely on a medical model of assessment (Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa, 2002; Adnams & Guthrie, 2001).

The current assessment tool that is completed by the medical doctor to determine whether the child is severely disabled and requiring permanent home care has serious defects and inadequately measures childhood disability and functioning. The tool gives little appropriate consideration for age-appropriate functioning, and is based exclusively on a medical model. It does not address the special or extra care needs of children with disabilities. The tool relies fundamentally on the assessor's interpretations (National Consultative Workshop Report, 2001) and there is also a lack of guidelines and training in the assessment procedure and use of the tool.

Consequently, children who do not meet these eligibility criteria are being assessed for eligibility, many of who are receiving the grant. Similarly, children who are entitled to the grant and should be eligible are being denied the grant. In practice, assessors and decision-makers do not strictly adhere to the legislative criteria as children with chronic conditions such as those in the final stages of HIV/AIDS, and children with terminal cancers are granted the benefit (Guthrie, 2002).

As the concept of the Care Dependency Grant dates back to pre-1994, non-governmental organisations, academic institutions and community groups concerned with children's and disabled persons' issues, have for many years called for the revision of the social assistance programme for children with disabilities. These sectors have predominantly advocated for an assessment instrument that adequately captures the social assistance needs of children with chronic health conditions. As a result, these sectors have been involved in discussions with the relevant government departments about the need for a revised assessment instrument (Adnams, 2002).

These sectors have engaged in national consultative workshops and meetings, where the limitations of the Care Dependency Grant has been clearly articulated and government has been challenged to rectify the programme (The Child Health Policy Institute, University of Cape Town & the Children's Rights Project, University of the Western Cape, 2000; National Consultative Workshop Report, 2001). A recommendation that was suggested based on these consultative processes is that the eligibility criteria for social assistance be determined on the basis of a needs-test, rather than a means-test. Thus, the sectors are advocating that income level no longer be a key determinant for eligibility to this benefit, but that the additional needs due to the disability and circumstances of the child and caregiver are given priority. It was also recommended that government assume a needs-based approach to the assessment process, incorporating social, environmental and other relevant factors.

Recent Developments

A further development is that the Regulations (No. 22852 of 2001) of the Social Assistance Act, 1992 (Act 59 of 1992) have been amended as of December 2001, introducing a Disability Panel as an alternative to the medical report submitted by the assessing doctor. This system of assessment may replace or compliment the medical doctor's assessment for the Care Dependency Grant, and does replace the Pension Medical Officer's final assessment of the application. Consequently, new assessment instruments are required for use by these assessment panels.

The researcher was employed to undertake a study as part of the preliminary process for the development of an appropriate South African tool. Based on the above-mentioned argument that the current South African tool is inadequate, it was determined that there is a need to investigate the use of social assistance assessment tools in other countries, and to assess their applicability to the South African context.

DERIVATION OF THE RESEARCH TOPIC

Preliminary reading of literature revealed that few assessment instruments specific to eligibility for social assistance were readily available. It was also found that much of the literature focussed on functional assessment in the health and rehabilitation domains. Additionally, minimal information is available pertaining to needs assessment of children with chronic health conditions. As a result, it was decided that the international social assistance assessment instruments that were accessible would be applied to the current South African social assistance context. In particular, it was decided that the assessment measures these instruments used to capture the needs of South African children would be examined.

THE OVERALL GOALS OF THE STUDY

Consequently, the following research aims and goals were developed due to the identification of themes and issues in the relevant literature.

Fundamentally, the study aimed to:

- Examine the application of two international instruments to the South African context for the purpose of making recommendations for the development of an appropriate South African assessment instrument; and
- Demonstrate through the application of international tools that there were areas of need related to children's chronic health conditions that were not presently provided for by the South African social assistance programme.

As a result, the following research objectives were determined:

- To identify the major categories of social assistance needs through the application of two international social assistance assessment tools; and
- To make recommendations for the inclusion of categories of need identified through the application of international social assistance assessment tools that are not captured in the current South African social assistance assessment tool.

Thus, the underlying assumption or hypothesis of this study was that two international instruments (the Australian Child Disability Assessment Tool and the United Kingdom's Disability Living Allowance instrument) would more appropriately capture the social assistance needs of children with chronic health conditions in a South African context.

RESEARCH DESIGN AND METHODOLOGY

Based on the above, this study was designed as a descriptive, comparative study of existing international instruments. Non-probability sampling was employed, and a combination of quantitative and qualitative data was analysed.

A small sample of 18 children from the Western Cape was selected, representing 6 types of chronic health conditions, specifically disability and chronic illnesses. These children were assessed for social assistance eligibility using the two international instruments. Their eligibility for the South African social assistance benefit was also assessed. Data collected from this process was recorded and analysed to identify commonalities and differences in data, as well as to determine the eligibility status of the children according to each country's legislative criteria.

Based on these processes, each tool was evaluated for its advantages and disadvantages as assessment instruments, and it's applicability to the South African context.

FINDINGS

Findings indicated that the child participants of this study experienced a wide variety of consequences as a result of their health conditions, such as their need for medical care, and their limited ability to perform life tasks. Additionally, the carers of the children identified a range of factors that impact on their ability to care appropriately for these children, such as their limited household income and lack of family support.

Regarding eligibility for the respective grants, the majority of the sample of children was not eligible for the South African grant based on the current system. In contrast, the large majority of the sample was eligible for the United Kingdom's benefit and the Australian benefit. The United Kingdom's tool was found to predominantly capture the needs of the children in the sample. However, the tool is impractical because of its length, inappropriate questions and cumbersome structure. The Australian tool was also found to capture the children with significant needs. This instrument is efficient and user-friendly.

CONCLUSION

The remainder of this report will present the literature review, methodology and findings of this study. Finally, conclusions and recommendations are provided pertaining to the aims of this study. The literature review in chapter 2 presents the international conceptual debates surrounding disability and health, as well as key approaches and definitions. This chapter also presents selected assessment instruments and measures used to assess children with chronic health conditions.

Chapter 3 details the design and methodology employed in this study. Hereafter, the findings of the study are presented and discussed in chapters 4 and 5. For ease of presentation, the researcher has separated the findings into two parts: part 1 (chapter 4) describes the data derived from the administration of the tools and

the outcomes of each tool. Part 2 (chapter 5) presents an analysis of the tools and discusses factors relevant to the South African context. Lastly, chapter 6 describes the conclusions of the study and makes recommendations for the improvement of South African social assistance policies and programmes.

CHAPTER 2: LITERATURE REVIEW

SOCIAL SECURITY ASSESSMENT TOOLS FOR CHILDREN WITH CHRONIC HEALTH CONDITIONS

This chapter presents a review of literature on social security assessment procedures, particularly focussing on assessment tools for determining social assistance eligibility for children with disabilities and chronic health conditions. Initially, the review considers the current social security context in South Africa. This is followed by a discussion of the international trends in the disability sector, highlighting common debates and definitions. The situation of persons with disability in South Africa is discussed before a look at measures of childhood disability and existing international assessment tools.

DEFINITION OF TERMS AND KEY CONCEPTS

Table 1 below contains the key terms used throughout this thesis. In the absence of reference to a source, the researcher's definitions in relation to the purpose of this study are supplied.

THE CONTEXT OF SOCIAL SECURITY IN SOUTH AFRICA

Social security interventions are attempts by the state and society to protect members from the loss of income and the extra costs due to social contingencies, or risks, such as unemployment, disability or pregnancy. Interventions occur as private measures, such as private medical aid schemes, and public measures. Public measures may be contributory, i.e., social insurance, such as the Unemployment Insurance Fund and non-contributory, i.e., social assistance grants, such as the State Old Age Pension and Disability Grant. Social security interventions can also be in the form of indirect services, such as free health care (National Consultative Workshop Report, 2001).

Table 1: Set of Key Definitions and Concepts

Social assistance eligibility: The State determines criteria for eligibility to a non-contributory cash transfer, e.g., based on income level, severity of disability, etc.

Means-test: Income level may be an eligibility criterion. A mean-test is administered to determine whether an individual or household's income level is below the determined income thresh-hold (National Consultative Workshop Report, 2001).

Assessment tool/instrument: The form that is completed and elicits information to determine eligibility for a social assistance benefit. These terms are used interchangeably in this thesis.

Condition: Broadly meaning state of health. It includes but is not limited to illness, impairment, disability, or other abnormal health symptom or manifestation (Stein, Bauman, Westbrook, Coupey & Ireys, 1993).

Chronic or ongoing health condition: The expression of the health condition over time. The concepts of duration and pattern of health condition are associated to this term (Stein et al., 1993). The concept includes impairments and disabilities.

Carer/Caregiver: The primary individual who has assumed the role for providing appropriate care, attention and supervision on a continuous basis for a person with a chronic health condition.

Treating health professional (THP): A qualified medical practitioner who would generally be the person who has the most knowledge of the child's medical condition, e.g. the medical specialist who has been treating the child (Commonwealth of Australia, 2001b).

Benefit decision-maker: The person responsible for deciding which applicants are eligible for the Disability Living Allowance based on the information provided in the assessment tools (Department of Social Security, 2000).

Needs: The needs that occur for a child with a chronic health condition as a consequence of his or her health condition. These may be identified as need for services, need for care, etc (Aron, Loprest & Steuerle, 1996).

However, a universal definition of social security does not exist. Social security systems differ between countries as the concept is based on ideological and political positions. South Africa is constitutionally bound to uphold the right for all to have access to social security, including social assistance. The White Paper for Social Welfare describes the domains of social security as "...poverty prevention,

poverty alleviation, social compensation and income distribution." (Dixon, 1986 in Ministry for Welfare and Population Development, 1997: 45).

Furthermore, the White Paper identifies four primary elements of the social security system:

a) Private savings - people voluntarily save for contingencies such as disability;

b) Social insurance - mainly consists of joint contributions by employers and employees to pensions or provident funds;

c) Social assistance - non-contributory and income or means-tested benefits provided by the State to groups such as people with disabilities who are unable to provide for their own basic needs. Social assistance in South Africa primarily assumes the form of social grants; and

d) Social relief - short-term measures to assist persons facing crisis situations, e.g. those affected by floods. This measure is also non-contributory (Ministry for Welfare and Population Development, 1997).

The present social security provisioning primarily aims at poverty alleviation, preventing destitution and ensuring an adequate standard of living (Guthrie & Sait, 2001). To accomplish this, the South African system primarily uses non-contributory measures, unlike countries such as America, which predominantly utilises contributory schemes.

For persons with disabilities, the White Paper for Social Welfare presents a strategy to ensure a social security system that is more accessible in relation to physical environment, procedures and communication methods. In addition, the strategy stipulates that options to provide financial support to care-givers of persons with disabilities will be explored, and that more effective assessment processes for grant application will be developed (Ministry for Welfare and Population Development, 1997). The following sections provide a discussion of disability issues both internationally and locally.

INTERNATIONAL TRENDS IN THE DISABILITY SECTOR

Perceptions Of Disability

The rights of persons with disabilities have become a global focus with the United Nations Decade of Disabled Persons from 1983 until 1992. A world wide move has been initiated, mainly spearheaded by persons with disabilities, resulting in an ideological shift towards perceiving disability as socially constructed, rather than as an inherent malfunction within the individual (McLaren, Philpott & Hlophe, 1997; Fougeyrollas, Noreau, Bergeron, Cloutier, Dion & St-Michel, 1998).

Thus the definition of disability is by no means conclusive. There remains debate between key role-players such as the disability movement and health professionals, including leading experts such as the World Health Organisation, about the true nature of disability. The fundamental difference lies in the perceptions of these groups with regards to the concept of disability.

The World Health Organization, in the International Classification of Impairment, Disability and Handicap (ICIDH) 1993 version provides a useful framework for understanding disability. They suggest a three-pronged concept:

- Impairments refer to the effects of disease at an *organic level*,
- Disability refers to the *personal level*, such as an impairment causing problems with walking or dressing, and
- Handicap refers to the *social level*, such as impairment and disability resulting in difficulties with participation in school, occupational or social activities.

(Ketelaar, Vermeer & Helders, 1998; van Niekerk, 1997).

These dimensions suggest very different perceptions of disability. Much of the controversy is associated with the fact that professionals tend to remain at the level of perceiving disability as impairment with the resultant disabling effects, while persons with disability are primarily concerned with the handicap level and the resultant social effects. This is reflected in the criticisms The World Health Organization received for their initial (1980) model of disability - organisations of persons with disabilities felt the model lacked the reality of the experiences of persons with disability in their daily contexts (Fougeyrollas et al., 1998).

Persons with disabilities perceive the problem as resulting from the social and physical environment, which they interact with continually. These environments disregard the needs of individuals, preventing persons with disabilities from full participation in society. In contrast, "Able-bodied professionals have seen the problem as being one of functional limitation of the impaired individual." (McLaren et al., 1997: 6).

The disability movement essentially seeks to reclaim medicine's view of the impaired body as a "...purely natural object..." and place it in the realm "...of history, culture and meaning..." (Hughes & Paterson, 1997: 326). Consequently, medical views that the impairment is the cause of persons with disabilities being restricted in social contexts has been severely challenged by the disability movement, who argue that the social system establishes barriers to their participation (Hughes & Paterson, 1997).

Considering the ICIDH's terminology, it appears that the debate centres around the particular emphasis that a group or individual ascribes to – whether the emphasis is on the impairment, disability or handicap level.

The diversion from the medical model of impairment and functional limitation to a social model of inclusion and equality is one that is essentially rights-based. The social model emphasises the role and responsibility that society plays in shaping the lives of its members, either through integration and provision or separation and isolation (McLaren et al., 1997). Thus the focus shifts from changing the individual, to eliminating the social barriers and hindrances that prevent persons with disabilities from participating fully as members of society. Essentially, the social model incorporates the social and economic disadvantages (van Niekerk, 1997) that may result from impairment, for example, the resultant income loss for an individual who has recently sustained a disability and can no longer work.

Definitions And Models Of Disability

Following from these perspectives of disability, various definitions of disability, and conceptual models exist to define disability. Previously, the World Health

Organization (1980 in McLaren et al., 1997: 5) believed disability to be "...any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being...". In contrast the Union of Physically Impaired Against Segregation (1976 in McLaren et al., 1997: 6) define disability as "...the disadvantage or restriction of activity caused by the way society is structured and organised which takes little or no account of people who have physical, sensory, or mental impairments...Disability is thus imposed on people with impairments who, as a result, become disabled not by their impairment but by society."

Another definition of disability that supports this view is that of the Institute of Medicine. They define disability as "...the expression of a physical or mental limitation in a social context – the gap between a person's capabilities and the demands of the environment." (Pope & Tarlov, 1991 in Hayley, Coster & Binda-Sundberg, 1994: 444).

These different definitions of disability illustrate the two perspectives discussed above, those of the social model, in the latter definitions and the medical model in the former. These two concepts of disability have very rarely been found to meet on common ground and have been the basis of differences between those working within the field of disability, and those who experience disability. Until recently, very little has been accomplished in attempts to unite or reconcile these two opposing positions.

The World Health Organization, in their latest edition of the ICIDH, now known as the International Classification of Functioning, Disability & Health (ICF), have developed a model that apparently integrates these two opposing approaches - the medical and social model. In their model, the World Health Organization claims to have assumed " ...a 'biopsychosocial' approach... in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective." (World Health Organization, 2001a: 20). Thus, the ICF is based on the integration of these two models, and seeks to include environmental and social factors as important dimensions of assessment.

Recognition of Contextual and Environmental Factors

It was recognised that a particular omission of the World Health Organization's (1980) initial classification of disability and diseases, is that of the environment as a key factor determining the impact of the disability on an individual's life. As a result, a general agreement has been recognised towards the end of the 1980's as to the importance of the relationship between the environment and the person experiencing a disability (Fougeyrollas et al., 1998).

As a consequence, the concept of environmental and contextual factors influencing the lives of persons with disabilities is evident in various models of disability, and particularly for assessment purposes. In fact, Haley et al. (1994) purport that this is not a new concept, and refers to assessment models of disability from the early 1980's. Furthermore, Fougeyrollas et al. (1998) identifies the relationship between the increasing interest and development of person-environment models of disability and efforts to achieve the implementation of social participation policies.

Various studies have highlighted the important role which context plays in the everyday functioning of persons with disabilities. Haley et al. (1994) demonstrate in their study of young children, some developing typically and others with severe disabilities, that both groups of children functioned differently in different settings. They make the observation that no physical activity or task can strictly be performed without the interaction of environmental factors or social context. This implies that environmental and contextual factors will either hinder or enhance the execution of tasks and activities. Specifically, Haley et al. (1994) observe that one cannot measure functional performance as abstract skills separate from contextual factors, and motivate for rehabilitation and assessment to occur within environmental settings as far as possible.

Hence, based on their findings, they state that function "...may best be described in a contextual framework rather than as a general abstraction of capability that can be generalized across many tasks and settings." (Haley et al., 1994: 448). The authors further highlight the responsibility of the clinician, therapist or any

professional conducting an assessment of an individual with an impairment, to consider the various environmental influences on the individual's functioning and well being.

Similarly, Gannotti, Handwerker, Groce and Cruz (2001) recognise that accurate interpretation of assessments of persons with disabilities requires assessors to examine the context and environment in which the individuals live. Thus cultural values and beliefs of a society regarding disability and health are also key considerations in one's assessment of environmental factors.

Significantly, Haley et al. (1994) relate the value of considering contextual factors when assessing the functional abilities of children, and state that it should be a primary factor in the measurement of childhood disability, particularly because of it's interaction with developmental factors. A holistic perspective is vital, one that considers the particular socio-economic and living conditions, as well as family relationships that play a role in the individual's life situation.

These kind of interactive models represent the principles of client-based programmes and rehabilitation that is interdisciplinary, systemic and holistic. As a result, these models are increasingly being used as a frame of reference for rehabilitation programmes and policy planning internationally, and have been mainly cultivated through the socio-political movement for the rights of persons with disabilities and clinical practice (Fougeyrollas et al., 1998).

Aron, Loprest and Steuerle (1996) write that essentially the different operational definitions of disability are chosen according to the type of programme or benefits a service provides. This decision should be informed by information on children's disabilities in particular contexts. The following section considers the situation of persons with chronic health conditions in South Africa.

CHRONIC HEALTH CONDITIONS IN SOUTH AFRICA

Previous research conducted in the disability arena has mainly focussed on quantitative studies. According to the Report of the ICIDH-2 Workshop (2000),

there is a huge gap in information on the experiences and opinions of persons with disability. Some of the limited literature available on the experience of disability in South Africa is discussed below.

The Socio-economic Context

In South Africa, pertinent factors that confound individuals' experiences of disability are poverty and inequality, societal attitudes and ignorance of disability, and a fragmented legislative framework regarding disability (Guthrie & Sait, 2001). It has been reported that South Africans who are disabled are disadvantaged in multiple aspects – not only are they disadvantaged as a result of their physical condition, but also because of their social and environmental conditions. Unfortunately, the legacy of apartheid still has repercussions on our society, with the majority of South Africans having experienced inferior education, and many still continue a lifelong struggle against poverty, unemployment and family and community dysfunction. This situation exists because of lack of access to healthcare, educational systems, and other social structures (van Niekerk, 1997).

Thus, a strong relationship between poverty and ill health exists in the South African context. The characteristics and impacts of poverty must be considered in light of this discussion of chronic health conditions. As poverty is not a static condition, it can impact on households due to lifecycle changes. Thus, shocks such as death of an income-earner or chronically ill family members can result in increased vulnerability to poverty (May, Rogerson & Vaughan, 2000).

Many studies in the South African Participatory Poverty Assessment (1998 in Budlender, 2000) indicate that a number of South Africans suffer from poverty-related illnesses. Tuberculosis and measles are examples of poverty-related illnesses in South Africa, as they result from working and living in unhealthy conditions. Consequently, persons with ill health find it difficult to secure and maintain stable employment. Additionally, if a family member requires part time or full time care, a family member is often obliged to forfeit his or her means of earning income and become the caregiver.

According to Budlender (2000: 119) "...chronic degenerative diseases are on the increase among disadvantaged communities." Due to the impact of poverty on the lives of disadvantaged South Africans, social grants have become a reliable source of household income security for millions (Budlender, 2000).

The psychological well being of persons with disability is also at great risk. Furthermore, the entrenched social conditions, such as violence and disease that many South Africans encounter daily perpetuates the increasing rate of permanent disability (van Niekerk, 1997).

The Prevalence of Disability

To illustrate the incidence of disability in South Africa, persons with physical disability in the Western Cape alone are estimated at 150 000. In this region, 48% of physical disability result from illness, 32,7% result from trauma, 9,4% from congenital disease, and 8,8% are of unknown origin* (Disler, 1986 in van Niekerk, 1997). Additionally, the highest incidence of physical disability is among black working-class populations. For example, in the black African residential area of Nyanga on the Cape Flats, it is estimated that there is one person with a disability in every seventh home (Disler, 1986 in van Niekerk, 1997).

This illustration of the Western Cape scenario does not do justice to the disability phenomena across the country, as the Western Cape is perceived as one of the richest provinces in South Africa. Indeed, a study on the extent of moderate and severe reported disability in South Africa reveals that Western Cape (3.8%) has the second lowest prevalence rate compared to other provinces (Schneider, Claassens, Kimie, Morgan, Naicker, Roberts & McLaren, 1999). This study found a national average prevalence rate of 5.9%, with Eastern Cape (8.9%), Kwa-Zulu Natal (6.7%) and Northern Province (6.3%) experiencing the highest disability prevalence rates in the country (Schneider et al., 1999).

A consequence of the conditions that persons with disabilities encounter is the environmental obstacles, particularly for persons with physical disabilities. In South

* Percentages as cited directly from the source do not add up to 100%.

African rural areas and townships, it is common for persons in wheel chairs to encounter rough and irregular terrain, potholed and slippery slopes on the route to the communal tap or bucket toilet (Hattingh, 1987 in van Niekerk, 1997). According to van Niekerk (1997: 236) the social and psychological functioning of persons with disabilities "...appears to be seriously compromised by the alienating environmental barriers which still prevail in South Africa."

Van Niekerk (1997) continues to explore the consequences of such social and environmental conditions and concludes that these conditions have extensive implications for persons with disabilities and those in their environment. Though we are concerned with children with disabilities in the South African context for the purpose of this study, factors that have implications for adults are likely to have greater implications for children. Groce and Zola (1993 in Gannotti et al., 2001: 1514) confirm that perceptions about children with disabilities are "...in part, a reflection of the opportunities and social roles available for adults with disabilities." The following section examines some of the issues pertaining to children.

Children with Disabilities

As indicated previously, disability is a complex phenomenon, with many factors influencing a person's experience of their disability (Schneider et al., 1999). For children, the issue is even more complex, as their disability places them at a greater level of vulnerability and need than children without a disability.

Aron, et al. (1996: 9) states that "...childhood disabilities are defined and measured in many different ways, depending on the purposes and needs of service providers...researchers, and policymakers." Thus, measures and prevalence rates of childhood disability are vital to inform appropriate and relevant programmes and policies related to childhood disability. A few statistics related to children with chronic health conditions in South Africa are presented below.

Similar to the adult population, 10 to 12% of children and adolescents have a disability (Harper, 1991 in van Niekerk, 1997). Recent research reveals that children with physical disabilities tend to be a higher risk group for psychological

maladjustment than their able-bodied peers. Additionally, researchers have found that 10% of children with chronic illnesses and disabilities would experience psychological difficulties. Additionally, young people respond with higher levels of distress than older people do to amputations, chronic illness and cancer (Frank, Elliott, Buckelew & Haut, 1988 in van Niekerk, 1997).

Considering these and other findings reflecting the vulnerabilities that children with disabilities encounter, it is imperative that structures are positioned to protect the most vulnerable members of society, our children. One such mechanism is a comprehensive social security system that protects children from risks and provides for the basic needs of children with disabilities, and one that attempts to alleviate some of the adverse social and environmental conditions that children experience.

Given the above discussion on international trends, it is apparent that there is an international move towards greater recognition of the rights and needs of children with disabilities.

The Rights of Children with Disabilities

The rights of children have become paramount as a result of many international initiatives to highlight the plight of children across the world. The key authoritative international instrument governing children's rights is the United Nation's Convention on the Rights of the Child. This was ratified by South Africa in 1995, and recognises children with disabilities as a vulnerable group requiring extra protection. The Convention expressly prohibits discrimination against such children (Guthrie, 2001). Furthermore, the Convention grants special attention and assistance to children with disabilities. It "...encourages, subject to available sources, assistance which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child." (Guthrie, 2001: 2).

Similarly, the African Charter of Human and Peoples' Rights, also ratified by South Africa, echoes the role of government in providing social security support where the family cannot provide such protection. With regard to South Africa's

responsibility to ensure that the rights of children are respected, the provisions of minimum benefits and adequate service delivery, Olivier (2001) states that in some respects, South African legislation is presently not congruent with the Convention on the Rights of the Child.

South Africa, having adopted many of the international instruments indicated above and others pertaining to rights-based practice, should be demonstrating these values within their systems and programmes. It therefore stands to reason that South Africa should also be moving towards a holistic, social approach to disability.

The current social security system for children with disabilities is, however, unsatisfactory, as described in the introductory chapter. The primary form of protection is a social assistance grant, which is non-contributory and means-tested. There are additional indirect benefits, such as free basic health care for children under six years and free primary education.

The following section considers existing approaches that measure childhood disability, and considers what an appropriate measure of the needs of children with disabilities should contain.

MEASURING THE NEEDS OF CHILDREN WITH DISABILITIES

Aron et al. (1996) reflects that existing classification and diagnostic approaches to measuring childhood disability are limited, as they do not include an adequate measure for determining the service needs of a child. Additionally, even the use of individualised service plans in early intervention and rehabilitative programmes do not adequately identify individual and family characteristics related to the child with a disability. Aron et al. (1996: 16) proposes that a solution would be to develop "...summary measures which efficiently capture the nature and extent of children's needs."

As a result of the lack of adequate measures in existing approaches, there has been a developing interest in the application of functional assessments, such as

those used in the domains of medicine and rehabilitation. These assessments are increasingly applied to other fields where measures of childhood disability play a significant role (Aron et al., 1996).

An Appropriate Measure Of Needs

According to Aron et al. (1996) an appropriate measure would account for the needs of a child with a specified profile of disabilities. Summary measures that explored the 'burden of illness' concept have been productive in medical and psychiatric contexts. A study on the length of hospital stays found the burden of illness to be closely related to a functional index of illness severity - the Computerized Severity Index. However, in a related study in a psychiatric setting, a similar severity index accounted differently for the hospitalisation outcome, relating it to primary diagnosis (Aron et al., 1996).

Similarly, for individuals with chronic conditions, the concept of 'burden of care' has been suggested as a way of summarising the combined needs related to the demand for services and resources. The application of summary measures has also been used in studies of families of children with multiple disabilities and chronic illness (Aron et al., 1996).

Additionally, a measure of disability should consider the unique context of a child in relation to the "...financial burdens of care, time costs for caregivers, and related measures of care-load for service systems." (Jacobs & McDermott, 1989 in Aron et al., 1996: 17). Therefore, summary measures must take cognisance of both condition and severity, to ensure that children who have similar disabilities but different levels of severity would have different burden of care weightings (Aron et al., 1996). As highlighted by Aron et al. (1996) the resultant needs of a child with a disability would incur financial costs for the caregiver of the child – thus the consequences of care for the caregiver and family should not be overlooked.

The following section examines various existing tools and frameworks in light of the above discussion. The section discusses health-related assessment tools for children with disabilities as well as specific social security assessment tools.

ASSESSMENT INSTRUMENTS AND RELEVANT FRAMEWORKS

The deficit in appropriate literature on qualitative research (Report on the ICIDH-2, 2000), and the lack of research related to children with chronic health conditions generally, has contributed to the lack of information on appropriate assessment instruments for children in South Africa. Hence, the following section describes instruments used internationally. A number of instruments were examined, however only a few were found to be relevant to this study. According to Fougeyrollas et al. (1998) although momentous strides have been accomplished with regards to the organic and functional consequences of disease and trauma, little has been gained with respect to the social consequences of disease, especially in daily life situations.

Instruments that were considered are the International Classification of Functioning, Disability and Impairment, the Functional Independence Measure, the Paediatric Evaluation and Disability Inventory, the Life-H Questionnaire and the Lifestyle Assessment Questionnaire. Additionally, the Australian Child Disability Assessment Tool and the United Kingdom's Disability Living Allowance tool are considered. All these instruments primarily focus on disability.

No tools were found that adequately assumed a holistic, needs-sensitive approach to children's chronic health conditions, incorporating social and environmental factors. However, a framework that considered children with chronic health conditions, including children with chronic illness is briefly described below.

The Non-Categorical Approach

A useful framework has recently been developed in America that is of particular relevance to this study, as the framework is used to identify children with chronic health conditions using a generic approach. A non-categorical framework allows children with diverse conditions to be grouped together, and is used primarily "...to assess the psychologic and social implications of living with ongoing health conditions." (Stein et al., 1993: 343). Based on this framework, children with chronic health conditions are not denied access to services or programmes because they have been diagnosed with a specific condition. This framework

therefore uses an approach, independent of the medical diagnoses, to identify children with chronic health conditions (Stein et al., 1993).

The framework is based on consequence of disease, that is the resultant symptoms, functional limitations and impairments of the condition, if any. By identifying the consequences of disease, one is able to determine the severity of the condition. An important consideration as well is the varying perceptions of the severity of the condition: the health professional may perceive the severity of the child's condition differently to the parents or the child. Using the framework, one is able to apply different perspectives, depending on the purpose of the assessment (Stein et al., 1993).

A useful characteristic of this framework is that the number of consequences created by the condition can be used as a measure of severity. Additional criteria can be included within various domains. The severity criteria can be varied and implemented depending on the purpose of the assessment and the programme outcomes. The essential concepts of the framework are disability or limitation of function, dependency and service needs. The authors have also developed measurable constructs from these concepts, and a screening tool (Stein et al., 1993).

The International Classification Of Functioning, Disability And Health (ICF)

The ICF and its predecessors are commonly referred to or used as a point of departure for some of the tools described below. For this reason, a short overview of the ICF is presented here.

The ICF is primarily a classification system, for the recording of information on the functioning & disability of individuals. This tool has been applied as a needs assessment tool as well as a social policy tool in various contexts, including the social security sector (World Health Organization, 2001a). Though the ICF is not specifically geared towards children and presents merely a framework, it nevertheless has valuable components for consideration. It is also widely accepted

as the international standard to describe and measure health and disability (World Health Organization, 2001b).

The purpose of the ICF is to provide a unified and standard "...framework for the description of health and health-related states. It defines components of health and health-related components of well-being." (World Health Organization, 2001a: 3). The ICF provides information on the functioning and disability associated with various health conditions. Additionally, the ICF provides a list of environmental factors, describing the context of individuals. However, the ICF remains fundamentally in the domain of health, and does not include circumstances that are not health-related, such as socio-economic factors (World Health Organization, 2001a).

It is structured in two segments, the first describes situations related to functioning and disability, and the second describes contextual factors. Each of these has two components. Table 2 below illustrates these components, their domains and categories or units of classification. These components, domains and categories provide a framework for describing possible situations with regard to an individual's functioning and any restrictions (World Health Organization, 2001a).

The functioning and disability segment of the ICF facilitates assessment in terms of 'negative' limitations and restrictions as well as 'positive' aspects of functioning. Additionally, environmental factors are considered in relation to their hindering or facilitating impact on an individual's disability and functioning. However, personal factors are not classified because of their associated cultural and social variance (World Health Organization, 2001a).

An individual's state is recorded by selecting the appropriate category code, and adding numeric codes or qualifiers that specify the extent of the functioning or disability in that category. Similarly, qualifiers are used to record the extent to which an environmental factor is a facilitator or barrier (World Health Organization, 2001a).

Table 2: An Overview of the ICF Classification System

	Functioning & Disability		Contextual Factors	
Components	Body Functions & Structures	Activities & Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning & disability	Internal influences on functioning & disability
Constructs	Change in body functions Change in body structures	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, & attitudinal world	Impact of attributes on the person
Positive aspect	Functional & structural integrity	Activities Participation	Facilitators	Not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers/ Hindrances	Not applicable
	Disability			

(Source: World Health Organization. 2001. *The International Classification of Functioning, Disability and Health*. Geneva.)

Functional Assessment Measures

The following section describes a few functional assessment tools specifically for children. An important link related to the previous discussions, is that assessment focussed on the 'disability level' is also known as functional assessment (Ketelaar, Vermeer & Helders, 1998).

Although there are a number of functional assessment instruments available for use with children with chronic health conditions, the majority are designed to assess motor function in children with developmental delay or motor disorders. Additionally, a literature review of instruments for the assessment of children with cerebral palsy revealed that most instruments were not adequately standardized, validated or reliable (Ketelaar, Vermeer & Helders, 1998).

Suitable health-related measures, specifically quality of life measures, are not as readily available for children as they are for adults (Mackie, Jessen & Jarvis, 1998; Stein et al., 1987). Of the instruments developed to measure the health and rehabilitation outcomes of children, few are relevant to children with chronic disabling conditions. In addition, they do not capture the relationship between the child's condition and social and environmental factors that impact on the child's well being. A further criticism of tools measuring child health conditions by Mackie et al. (1998: 475) is that there is "...a tendency to neglect generic measures for use with disabling childhood conditions."

Mackie et al. (1988) suggest that an instrument developed to measure the impact of disability on the lives of children should contain the following aspects:
1) It should provide a synopsis of the child's experiences based upon a systematic representation of a number of appropriate dimensions;
2) It should assess the impact of impairments or disabilities on the life of the child, not focus on the impairment or disability; and
3) It should create a single score based on a continuous or quasi-continuous scale.

In light of the characteristics of the ICF the following section will examine a few tools that are adaptations of the ICF or its predecessors. The instruments discussed in this section predominantly have a medical purpose and background – however, they do include social and environmental factors to varying degrees.

The Lifestyle Assessment Questionnaire (LAQ)

Though this questionnaire was developed initially to assess children with cerebral palsy, the authors give the assurance that "...there is little that constrains its use to that condition." (Mackie et al., 1998: 484). They further justify it's use for other health conditions by stating that the tool requires minor modification to be applicable to children who are disadvantaged by conditions other than cerebral palsy.

The function of the LAQ is primarily "...to describe the impact of impairment and disability on the lives of children with cerebral palsy and their families." (Mackie et al., 1998: 473). The tool has also been tested as a reliable and valid measure of the impediments experienced by children with cerebral palsy (Mackie et al., 1998).

Significantly, the tool is based on the dimensions contained in the ICIDH. A core reason for the adaptation of the ICIDH in the manner pursued by Mackie, et al. (1998) is that the ICIDH is a classification system designed specifically for adults, therefore lacking applicability to children experiencing disability, and lacking specificity regarding a mechanism whereby classifications can be made. Similarly the Report on the ICIDH-2 Workshop (2000) reflected that the ICIDH-2 was not child-friendly and required modification to be used as a tool to assess child disability.

Thus, the ICIDH is used as a point of reference with regards to terminology as well as other considerations. The authors attempt to operationalise the definitions and dimensions recommended in the ICIDH. An illustration of this is that of the term 'handicap', which is used by the ICIDH to describe the interaction between the person with impairment and his or her environment. Mackie, et al. (1988) uses the term 'handicap' to signify 'impact of disability', and thus differentiate between these frequently confused terms - disability and handicap. This definition of handicap is the core concept underlying the development of the tool.

The tool therefore retains the ICIDH model of describing the impact of disability along certain dimensions. They expand this model by including both medical and social experiences, and have developed a tool that can measure at a given point in time, the impact of cerebral palsy on the lives of children and their families (Mackie et al., 1988).

The initial step to developing the LAQ was adapting an existing tool. The tool chosen was developed on the basis of the ICIDH dimensions and was specific to children with cerebral palsy. After this process, a set of 46 items was created (Mackie et al., 1988). The 46 items are summarised in Table 3 below in their respective dimensions.

Table 3: Items of the Lifestyle Assessment Questionnaire

Physical Independence	*Clinical Burden*	*Mobility*	*Schooling*	*Economic Burden*	*Social Integration*
Assistance required in fulfilling certain activities of daily living: e.g., washing hands, climbing stairs, doing up buttons	Frequency of doctors' appointments in the last year	Furthest distance/ range the child covered (in yards) unaided in the last week	Type of school attended	Cost of special equipment in the last year	Number of adaptations made to the family home in the last year
Other dependency/ restraint needed	Number of weeks spent in plaster/ wearing body or leg support in the last year	Ability to leave family home unaided	Time taken to get to school from home	Other financial costs to the family in the last year	Number of adaptations to the family home still required
Frequencies of sleep disturbances over the last week	Number of operations in the last year	Number of outings unaccompa ni-ed in last week		Changes in parental employ-ment	Availability of local help
Weight-related burden of lifting/carrying the child	Length of hospital stay(s) in weeks in the last year	Number of outings requiring transport in last week		Use of a special diet	Effects on parental social life
	Number of items of special equipment in the home	Purposeful movement & co-ordination			Difficulty in organising family holidays
	Frequency of therapists' appointments in the last year	Proportion of rooms in the home accessed by child in the last week			Social stress on siblings
	Number/ frequency of fits/blackouts in the last year	Proportion of rooms in the home accessed unassisted			Social stigma
	Number of medicines taken yesterday				Isolation from natural parents
	Referral for behavioural problems over the last year				Social stress on parents
	Number of special services needed (e.g. therapies)				Number of friends the child has seen outside of school in the last week

(Source: Mackie, P., Jessen, E. and Jarvis, S. 1998. The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: Care, Health and Development*, 24(6): 473 - 486.)

These items were converted into 37 questions, written appropriately for the response of caregivers. The questions focussed on the child's functioning related to what the child did every day. The questions asked for a response "...within a specific, actual time period (e.g. 'in the past week')..." (Mackie et al., 1988: 476).

The dimensions were derived "...using multidimensional scaling analysis..." (Mackie et al., 1988: 478). The dimension of clinical burden was identified as a result of the scaling analysis. This dimension reflects the increase of the family's need for numerous and continuous contact with professionals and services. The dimensions proposed in the ICIDH have been adapted to accommodate children's particular circumstances e.g., occupation has been changed to schooling (see Table 4 below for a comparison of the ICIDH and LAQ dimensions). Mackie et al. (1998) concludes that the impact of the child's health condition on the family emerges as a significant issue; hence it's representation in the LAQ's dimensions and items.

Table 4: Comparison of Dimensions

ICIDH Dimensions	LAQ Dimensions
Orientation	-
Physical independence	Physical independence
Mobility	Mobility
Occupation	Schooling
Social integration	Social integration
Economic self-sufficiency	Economic burden
Other	Clinical burden

(Source: Mackie, P., Jessen, E. and Jarvis, S. 1998. The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: Care, Health and Development*, 24(6): 473 - 486.)

The authors provide an assessment of the LAQ in terms of the aspects that such a tool should contain as indicated above, and confirm that the LAQ meets these requirements. On practicalities, the LAQ takes approximately 20 minutes to complete, and is viewed as user-friendly by both caregiver and professional. Finally, it is the authors' opinion that the LAQ provides a measure of the child and

family's perspective of the child's health condition, and thus does not rely on the clinician's perception of the child's experience (Mackie et al., 1998).

The Life–H Questionnaire

Similarly, Fougeyrollas et al. (1998) developed a measurement tool, adapted from the ICIDH. The tool has successfully been tested for reliability on children as well as adults with disabilities. The tool attempts to measure the life habits of an individual, i.e., the individual's activities of daily living and social roles. It aims to determine the extent of disruption in life habits of persons with disabilities, in other words, identifying the 'handicap' situations experienced by persons with disabilities (Fougeyrollas et al., 1998).

Thus, the tool represents a conceptual model of 'the handicap process', illustrating the interaction between the functional and organic consequences of disease and the contributing environmental factors (Fougeyrollas et al., 1988). In this model, life habits are defined as "... habits that ensure the survival and development of a person in society throughout his or her life." (Fougeyrollas et al., 1988: 130).

Based on the life habits described in Table 5 below, The Life-H assessment tool was developed to assess and document the person-environment interaction, particularly to determine the life situations that can generate and perpetuate difficulty in the accomplishment of life habits for persons with disabilities (Fougeyrollas, et al., 1998: 132).

Hence, the LIFE-H was designed to consist of items that are congruent with the 13 categories indicated in Table 5. The final output resulted in a form including 248 items, as well as a more general version containing 58 items. Fougeyrollas et al. (1998: 133) provide examples of items in the LIFE-H questionnaire: "Holding a conversation" (communication), "Taking bath or shower" (personal care), and "Planning your budget..." (responsibility). There are varying numbers of items corresponding to each category, i.e. nutrition has 18 items while fitness has 9 items (Fougeyrollas, et al., 1998).

Table 5: Life Habits

Activities Of Daily Living	Social Roles
Nutrition – diet, food preparation, meals	Responsibility - financial responsibility & responsibility towards others
Fitness – sleep, physical & mental fitness	Family relations - affective family relations, marital relations, parental care, other parental relations, relations with other relatives
Personal care - hygiene, excretory hygiene, dressing, health care	Interpersonal relations - sexual, affective & social relations
Communication - expression & reception of information	Community - consumption of goods & services, voluntary associations, religious groups
Residence - housing, maintenance, furnishing & other household appliances	Education - pre-school, school, occupational, other training
Mobility - limited mobility, transportation	Employment - counselling, search of employment, paid & unpaid employment
	Recreation - sports & games, arts & culture, other habits

(Source: Fougeyrollas, P., et al. 1991. The handicap creation process. In: Fougeyrollas, P., Noreau, L., Bergeron, H., Cloutier, R., Dion, S-A. and St-Michel, G. 1998. Social Consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *International Journal of Rehabilitation Research*, 21(2): 127 - 141.)

A measurement scale was developed in relation to these life habit items, and is based on two concepts: the level of difficulty experienced when performing a life habit, and the type of assistance required to accomplish a life habit.

Two questions are asked in the questionnaire, preceding the list of life habits:

1. "For each of the following life habits mark how you generally accomplish it and with what type of assistance."
2. "For each of the following life habits indicate your degree of satisfaction or dissatisfaction with the way you generally accomplish it."

(Fougeyrollas et al., 1998: 134)

Thus, the person completing the form should indicate the degree of difficulty experienced ('no difficulty, with difficulty, performed by substitution, not performed, not applicable') when completing a life habit. Additionally, the respondent should indicate the type(s) of assistance required when accomplishing a particular life habit: 'no help, technical aids, adaptation, human assistance'. If an individual due to personal preference does not attempt a particular life habit, this habit should be marked as 'not applicable'. The individual's level of satisfaction with the

accomplishment of each life habit can also be indicated on the form, but these responses are not included in the scoring process (Fougeyrollas et al., 1998: 132-4).

An accomplishment scale was developed from an integration of these two concepts – the degree of difficulty and assistance required, on a continuum of 10 levels. A score is obtained for each category by adding the accomplishment score of each applicable item. The total LIFE-H score is obtained by calculating the sum total of the 13 habit categories. A computer programme has also been developed to assist with the scoring process (Fougeyrollas et al., 1998).

Fougeyrollas et al. (1998) indicates the significance of including the concept of type of assistance. Particularly if human assistance is required, it impacts greatly on the degree of accomplishment in comparison to the accomplishment of a habit that does not require the assistance of another person. In fact, the level of accomplishment "Performed by substitution" specifically acknowledges that some life habits need to be performed entirely by another person, as the person with an impairment does not or cannot actively participate in that activity (Fougeyrollas et al., 1998: 136). However, this does not affect the scoring process, as each type of assistance is given equal value. This differentiation is most useful for analysis and for clinical intervention (Fougeyrollas et al., 1998).

The inclusion of a satisfaction scale is useful, as it records the subjective assessment of the individual's accomplishment of tasks for daily living. This information can be perceived as an indicator of quality of life, as well as identifying the specific life tasks that frustrate an individual's quality of life and prioritising these for intervention. Therefore, this particular measure seeks to obtain not just quantity but quality of social participation (Fougeyrollas et al., 1998).

The Pediatric Evaluation Of Disability Inventory (PEDI)

The PEDI was developed to measure the functional abilities and performance of children between the ages of 6 months and 7 years. However, it can be used for the evaluation of older children if they are functioning at the level of a 7 year-old or

younger. It was designed to serve as a descriptive and discriminative measure to identify functional delay (Haley, 1997).

The purpose of the PEDI is to collate information regarding a child's typical performance in his or her significant environments. It consists of two dimensions: functional skills and caregiver assistance, and covers the content domains of self-care, mobility, and social function. The dimension of functional skills measures the performance of functional tasks and activities, containing a set of behaviours that are perceived as vital for daily functioning. The caregiver assistance dimension measures the degree of help required to accomplish these complex tasks (Haley et al., 1994). The functional skills dimension and the caregiver assistance dimension are indicated below in Tables 6 and 7, respectively.

In the content domains, functional activities are measured by the identification of skills that the child has already mastered and has shown competence. Items for these domains were selected by the identification of meaningful component units that comprise complex tasks. A modification scale is also included, providing a measure of the environmental modifications and equipment used by the child to accomplish daily activities (Haley, 1997).

The PEDI can be administered by professionals who have knowledge of the child's condition, or by a structured interview of the parent. The parent interview can be completed in approximately 45 minutes (Haley, 1997).

The PEDI consist of 4 sections:

- Section 1 requests basic biographical information about the child concerned, the respondent, the interviewer, and the assessment;
- Section 2 is the start of the questionnaire, listing 197 discrete items of functional skills in the 3 content domains;
- Section 3 lists the caregiver assistance and modification items in the 3 content domains; and
- Section 4 consists of the score sheet.

Table 6: Functional Skills in the 3 Content Domains of the PEDI

(one item from each category is included here)

Self-Care	Mobility	Social Function
Food texture: Eats ground/lumpy foods	Toilet transfers: Get on & off adult-sized toilet	Comprehension word meanings: Orients to sound
Use of utensils: Finger feeds	Chair/wheelchair transfers: Sits unsupported on chair or bench	Comprehension of sentence complexity: Understands directions that describe where something is
Use of drinking containers: Holds bottle or spout cup	Car transfers: Manages seat belt or chair restraint	Functional use of communication: Names things
Toothbrushing: Holds toothbrush	Bed mobility/transfers: Gets in & out of own bed	Complexity of expressive communication: Uses 4-5 word sentences
Hairbrushing: Brushes or combs hair	Tub transfers: Climbs or scoots in & out of tub	Problem-resolution: Faced with an ordinary problem, child can join adult in working out a situation
Nose care: Allows nose to be wiped	Indoor locomotion: methods- Walks without support	Social interactive play (Adults): Initiates a familiar play routine
Handwashing: Dries hands thoroughly	Indoor locomotion: distance/speed- Moves within a room with no difficulty	Peer Interactions (Child of similar age): Plays activities or games that have rules
Washing body & face: Dries body thoroughly	Indoor locomotion: pulls/carries objects- Moves objects along floor	Play with Objects: Puts together materials to make something
Pullover/front-opening garments: Puts on T-shirt, dress or sweater	Outdoor locomotion: methods- Walks without support	Self-Information: Can state first name
Fasteners: Snaps & unsnaps	Outdoor locomotion: distance/speed- Moves 100-150 feet	Time Orientation: Has very simple time concepts
Pants: Puts on pants with elastic waist	Outdoor locomotion: surfaces- Up & down curbs	Household chores: Beginning to help care for own belongings if given constant direction & guidance
Shoes/Socks: Puts on socks	Upstairs: Walks up partial flight	Self protection: Shows appropriate caution around stairs
Toileting Tasks: Tries to wipe self after toileting	Downstairs: Walks down partial flight	Community function: Makes transactions in neighbourhood store without assistance
Management of bladder: Consistently stays dry day & night		
Management of bowel: Indicates need to be changed		

(Source: Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. and Andrellos, P. 1992. Pediatric Evaluation of Disability Inventory. (version 1.0) In: Haley, S. 1997. The Pediatric Evaluation of Disability Inventory (PEDI). *Journal of Rehabilitation Outcome Measurement*, 1(1): 61 - 69.)

Table 7: Summary of the PEDI Caregiver Assistance and Modification Items

Self-Care	Mobility	Social Function
Eating: eating & drinking regular meal	Chair/Toilet Transfers: child's wheel-chair, adult-sized chair, adult-sized toilet	Functional Comprehension: understanding of requests & instructions
Grooming: brushing teeth, brushing & combing hair & caring for nose	Car Transfers: mobility within car/van, transfers	Functional Expression: ability to provide information about own activities & make own needs known
Bathing: washing & drying face & hands	Bed Mobility/Transfers: getting in & out & changing positions in child's bed	Joint Problem Solving: include communication of problem & working with caregiver or other adult to find a solution
Dressing Upper Body: all indoor clothes	Tub Transfers: getting in & out of adult-sized tub	Peer Play: ability to plan & carry out joint activities with a familiar peer
Dressing Lower Body: all indoor clothes	Indoor Locomotion: 50 feet (3-4 rooms)	Safety: caution in routine daily safety situations
Toileting: clothes, toilet management or external device use, & hygiene	Outdoor Locomotion: 150 feet on level surfaces, focus on physical ability to move outdoors	
Bladder Management: control of bladder day & night	Stairs: climb & descend a full flight of stairs (12-15 steps)	
Bowel Management: control of bowel day & night		

(Source: Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. and Andrellos, P. 1992. Pediatric Evaluation of Disability Inventory. (version 1.0) In: Haley, S. 1997. The Pediatric Evaluation of Disability Inventory (PEDI). *Journal of Rehabilitation Outcome Measurement*, 1(1): 61 - 69.)

In section 2, the respondent is requested to score the child's ability to perform the task by indicating:

> "0 - unable, or limited in capability, to perform item in most situations, or
> 1 - capable of performing item in most situations, or item has been mastered and functional skills have progressed beyond this level."

(Source: Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. and Andrellos, P. 1992. Pediatric Evaluation of Disability Inventory. (version 1.0) In: Haley, S. 1997. The Pediatric Evaluation of Disability Inventory (PEDI). *Journal of Rehabilitation Outcome Measurement*, 1(1): 61 - 69.)

In Section 3 the respondent is requested to score the caregiver's level of assistance in the self-care, mobility and social domains by circling the appropriate score for each item, as listed in Table 7. The caregiver assistance scale consists of:

"5 = Independent; 4 = Supervise / Prompt / Monitor
3 = Minimal assistance; 2 = Moderate assistance
1 = Maximal assistance; 0 = Total assistance"

(Source: Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. and Andrellos, P. 1992. Pediatric Evaluation of Disability Inventory. (version 1.0) In: Haley, S. 1997. The Pediatric Evaluation of Disability Inventory (PEDI). *Journal of Rehabilitation Outcome Measurement*, 1(1): 61 - 69.)

Similarly, the respondent is requested to score the type of modification required by the child to accomplish each item in the 3 content domains, as listed in Table 6. The modification scale is as follows:

"N = No modifications; C = Child-oriented (non-specialized) Modifications
R = Rehabilitation Equipment; E = Extensive Modifications"

(Source: Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. and Andrellos, P. 1992. Pediatric Evaluation of Disability Inventory. (version 1.0) In: Haley, S. 1997. The Pediatric Evaluation of Disability Inventory (PEDI). *Journal of Rehabilitation Outcome Measurement*, 1(1): 61 - 69.)

Social Security Assessment Instruments

Social security assessment procedures generally incorporate a process of the individual with the disability, or a custodian or caregiver, applying for the relevant benefit from the social security body responsible for the provisioning of these benefits. This body assesses every applicant according to predetermined, legislated eligibility criteria (Lennie & Van Hemel, 2002).

In order for the assessment to occur rapidly and as accurately as possible, the applicant would be required to complete an application form, also known as a claim form, and provide all relevant data to enable the decision-makers to make an accurate and informed assessment. Depending on the legislation governing social security, parts of these forms may need to be completed by a particular professional, e.g. a medical professional. In some countries, such as Australia, two sets of forms need to be completed, one by the person claiming the benefit, and

the other by a health professional (Common Wealth of Australia, 2001a). These assessment tools or instruments require thorough and in-depth planning and design to ensure that it efficiently captures the most pertinent information required for the assessment.

This research study and the remainder of this review will focus on the evaluation of two social security assessment tools - one developed and employed by the United Kingdom, the other by Australia. An analysis of these tools, and comparison with the current South African tool is hoped to provide a basis for the development of a new South African tool.

The Child Disability Assessment Tool (Australia)

The Child Disability Assessment Tool (CDAT) and the related assessment process is governed by the Child Disability Assessment Determination of 2001, made under section 38D of the Social Security Act, 1991 (Act S 479 of 1991) (Commonwealth of Australia, 2001a).

The development of the tool was initiated in 1993 and involved the participation of community organisations. Medical reference groups, child advocacy and disability groups comprised the consultant team for the development and testing of the tool. The tool has successfully been tested against validity, reliability, bias and administration criteria (refer to Appendix A).

The CDAT is designed as a test to assess the functional ability, emotional state, behaviour and special care needs of a person under 16, to determine whether the young person's caregiver is eligible for the Carer's Allowance, formerly known as the Child Disability Allowance (Commonwealth of Australia, 2001a).

The CDAT measures a young person's level of functional ability or disability according to age-appropriate standards in the areas of communication, feeding, self-care, social and community skills as well as mobility. In addition, it considers the young person's behaviour and special care needs. The assessment is administered through the use of two questionnaires focussed on these

components – one for the child's treating health professional and the other for their caregiver.

The CDAT is purposed to identify "...a significant level of disability regardless of the type of disability or condition." (Commonwealth of Australia, 2001d: 1). Therefore, the CDAT is aimed at determining the impact of the child's inability to function in important areas on the child and the family. It does not measure the care and attention required by the child, nor does it measure all possible functional abilities (Commonwealth of Australia, 2001d).

According to the Guide to Social Security Law (Commonwealth of Australia, 2001e), functional abilities are actions that a child should be able to accomplish at several age-related developmental milestones. Given this, the definition of a disabled child, whose carer would qualify for the Carer's Allowance, is *one who has sufficient functional impairment to require care* (Commonwealth of Australia, 2001f).

If a child does not have a recognised disability, the instrument enables a score to be calculated based on age-related milestones, from the health professional and caregiver's questionnaires, which serves as a test of qualification for the benefit.

Thus, a child would need to satisfy the following criteria:

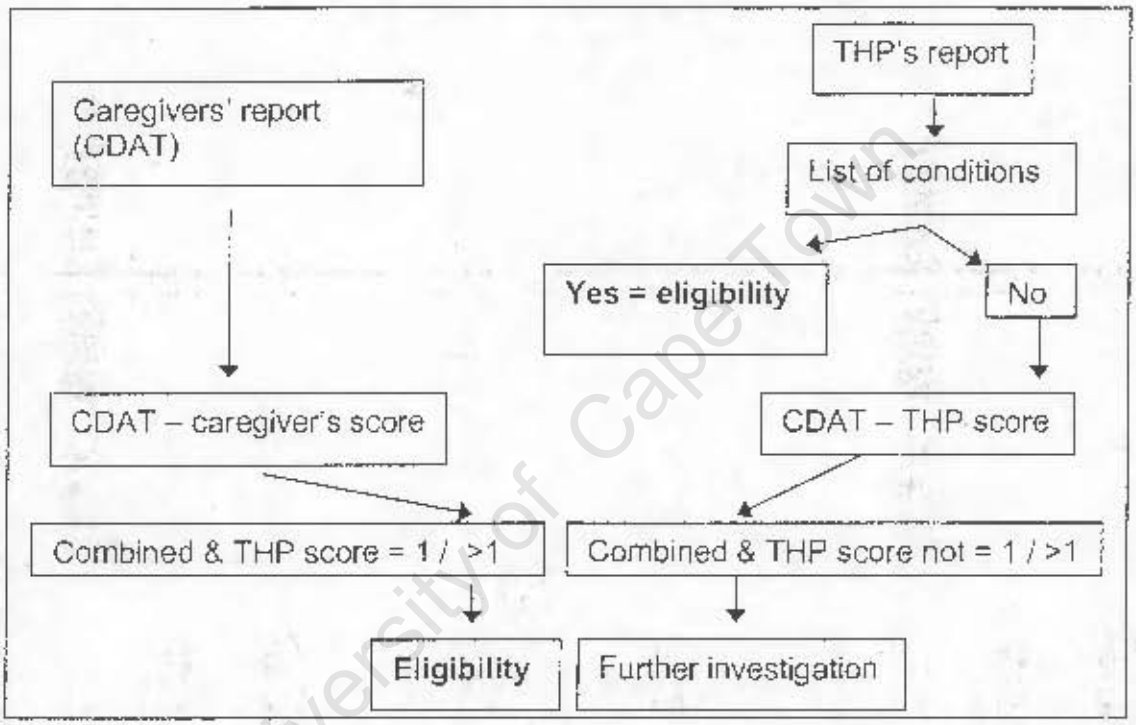
1. Suffer from a physical, intellectual or psychiatric disability AND
2. A recognised disability as stipulated in the Child Disability Assessment Determination (Commonwealth of Australia, 2001a: 42 – 44), OR
3. Be assessed under the CDAT and
   - Has been granted a Treating Health Professional score above zero AND
   - Has been granted an overall CDAT score of +1 or higher AND
4. Is likely to suffer from the disability permanently or for an extended period of time.

(Commonwealth of Australia, 2001f: 1)

The THP and the caregiver scores determine whether or not a child is eligible for the benefit. The test is also recognised as complete and requiring further

investigation once a score has been obtained from the THP's questionnaire alone, and the score is *greater than zero but less than +1*. This only occurs if a child has not met the criteria above. The scoring phase consists of eleven distinct steps, and includes the application of a rating method (Commonwealth of Australia, 2001c: 1). (Refer to Appendix B for a summary of the scoring process applied to the CDAT). Figure 1 below illustrates the researcher's conceptualisation of the assessment process.

Figure 1: Assessment Process for the Australian Benefit



If a child does not have sufficient functional impairment to obtain a qualifying score on the CDAT, or does not suffer from a condition stipulated in the list of conditions, the child's caregiver might be eligible for a Health Care Card. The Card can assist families by reducing some of the medical expenses children with health conditions may incur (Notes for Carer Allowance, 2001). A child can qualify for this indirect benefit if the child's additional care and attention needs are above that expected of peers without a disability, and the child's additional needs exceed 14 hours per week (Refer to Appendix A).

The applicant is required to complete a basic claim form, as well as a second questionnaire, the functional assessment. A comprehensive summary of the claim form and the functional assessment is provided in Appendix B.

The Functional Assessment

The functional assessment consists of two sections: the first section measures the child's functional ability in key functional domains, while section two addresses the behaviour and special care needs of the child. The form is structured in a checklist fashion.

The first section measures the child's functional ability in the following areas: communication; feeding and mealtime skills; hygiene and grooming skills; dressing skills; social and community skills; and hand and body movement. A list of nine or ten options is provided in each functional area, describing abilities or skills that a child should master at each developmental stage. The applicant is requested to choose one ability or skill out of the range, that best describes the child's functioning within each domain.

The second section describes various behavioural difficulties and special care needs. The applicant is required to indicate all the options that apply to the child concerned. The CDAT is predominantly a functional assessment, and has a greater emphasis on the medical report than the caregiver's report.

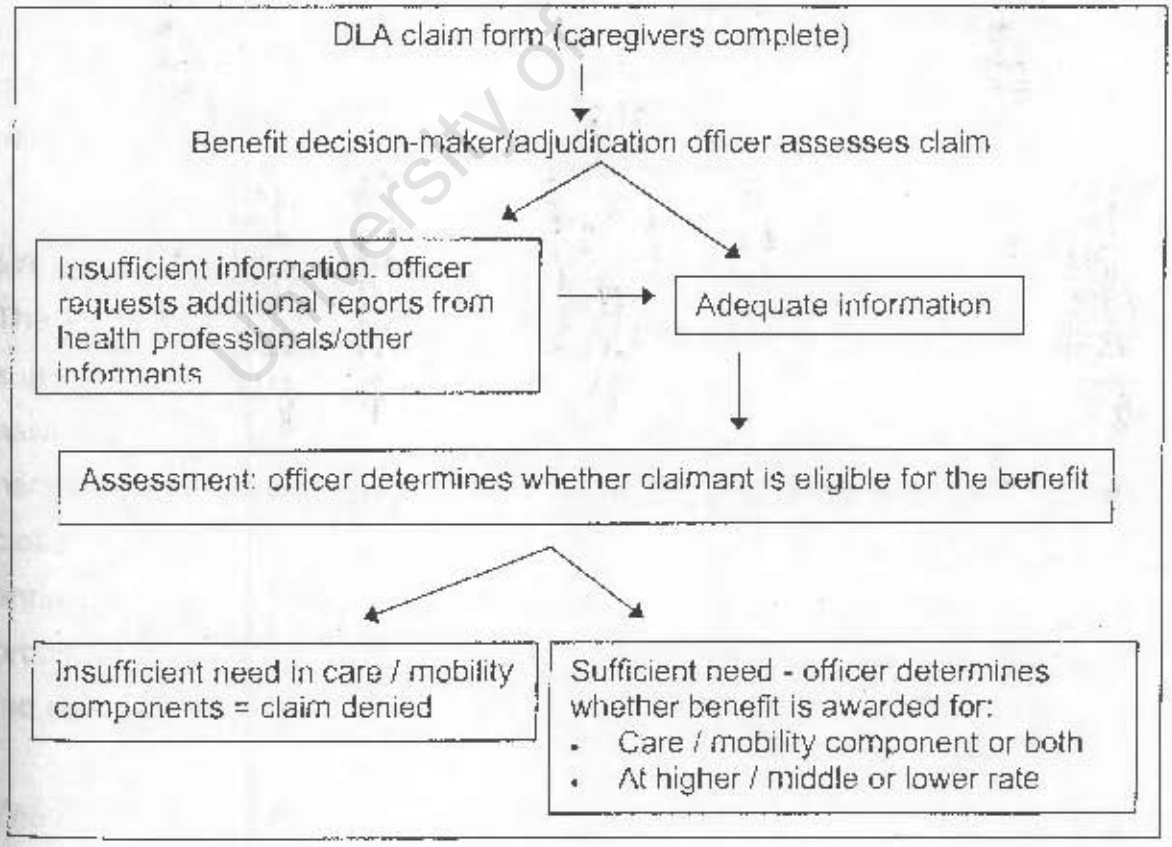
Disability Living Allowance for Children under 16 (UK)

The Disability Living Allowance (DLA) is a tax-free social security benefit for adults and children with disabilities that was introduced in the United Kingdom in 1992. The administration of the benefit involves self-reporting by the applicant and adjudication by lay officials. A Disability Living Allowance Advisory Board was established in 1991 as an independent statutory body, responsible for advising the State on matters relating to the DLA. The Board, composed of persons with disabilities, a carer and health professionals, also plays a role in advising and training the Social Security Benefits Agency staff members and the adjudication officers (Disability Living Allowance Advisory Board, 1998).

Payment of the benefit is independent of income, not means-tested, and persons in hospital or residential care are not eligible. For children under 16, the benefit is paid for a child with a physical or intellectual disability or illness if they require extra care and attention than is appropriate for their age, as a result of their disability or illness (Social Security Benefits Agency, 2001).

The assessment considers two aspects - the mobility and care needs of the child. The care component has three payment rates, while mobility has two. A child can receive benefits from either one or both components. For verification, a statement from the child's medical practitioner, or any person who has knowledge of the child's condition is required, simply describing the disabling condition and it's effect on the child. If the benefit Decision-Maker requires a medical report on the child's condition, a report may be requested from the child's doctor (United Kingdom, Department of Social Security, 2000). Figure 2 below reflects the researcher's conceptualisation of the assessment process.

Figure 2: Assessment Process for the United Kingdom's Benefit



An important point of departure for the United Kingdom's focus on disability assessment is that the *effects* of the disabling condition rather than the disability itself are the main considerations (United Kingdom, Department of Social Security, 2000).

Children can receive the DLA if the child has care and mobility needs, which exceeds the normal requirements of children of the same age. Children can access the care component from as young as 3 months of age, but can only access the mobility component from the age of three years. Furthermore, care and mobility needs must have been present for at least 3 months prior to application, and should continue to be present for the following 6 months (Social Security Benefits Agency, 2001). Additionally, children should have an unrestricted residency right to live in Great Britain, and should have been resident for at least 6 months of the year prior to application (United Kingdom, Department of Social Security [no date, b]).

Special concessions apply to children who suffer from a terminal illness: they receive payment immediately on process of their application, the 3-month qualifying period is waived, and their claims are prioritised. Additionally, a doctor's report is compulsory (United Kingdom, Department of Social Security, 2002).

Care and Mobility Components

The care component is representative of two kinds of needs: attention and supervision needs. Attention needs are related to the child's need to have a carer assist him or her with personal care that he or she is unable to conduct for him or herself. Supervision needs are related to the child's need to have someone in close proximity to ensure that the child is kept out of danger and does not endanger anyone else. The mobility component is for children who experience problems with walking or moving (United Kingdom, Department of Social Security [no date, a]).

The higher rate of the care component is awarded if:

- The child requires frequent assistance related to bodily functions from a carer for both the day and the night; or
- The child requires supervision from a carer during both the day and night to prevent danger to the child or others; or
- The child requires assistance with bodily functions during the day and supervision during the night, or vice versa; or
- The child is terminally ill.

(United Kingdom, Department of Social Security [no date, a])

The higher rate of the mobility component is awarded if:

- The child cannot walk; or
- The child is virtually unable to walk; or
- The child has had both legs amputated above the ankle, or was born without legs or feet; or
- The exertion required to walk would endanger the child's life or lead to a deterioration in the child's health; or
- The child is both deaf and blind; or
- The child is entitled to the higher rate of the care component and is severely intellectually impaired with extremely disruptive behavioural problems.

(United Kingdom, Department of Social Security [no date, b])

The Middle Rate, for the Care Component only, is awarded if:

- The child requires assistance or supervision from a carer either during the day or during the night.

The Lower Rate for the Care Component is awarded if:

- The child requires assistance or supervision for a significant portion of the day.

The Lower Rate for the Mobility Component is awarded if:

- The child who is able to walk requires guidance or supervision from a carer most of the time when walking out of doors; and
- The child requires substantially more guidance or supervision from a carer than other children of the same age require.

(United Kingdom, Department of Social Security, 2002: 61520 - 61524)

A child may be the recipient of only one award rate. If a child's condition changes significantly, warranting change in the award from a lower rate to a higher rate, the child must satisfy the condition for the higher rate for at least three months to qualify for a change in award rates (United Kingdom. Department of Social Security, 2002).

Structure of the Instrument and Information Requested from the Applicant

The claim form for the Disability Living Allowance is divided into two sections: the first section requesting basic information on the claimant's details. A summary of section 1 is provided in Appendix D.

The second section of the claim form requests information on how the child's disability or illness affects them. These questions are the more pertinent ones, as these are used to capture the nature and resultant needs of the child's illness or disability. The applicant is requested to be very specific when providing details about the child's condition, to the extent that measurements of time are used to elicit the degree of care and supervision a child requires for a range of activities of daily living (refer to Appendix D).

The applicant is requested to provide detailed and descriptive information about the child's difficulties to perform a range of activities such as walking, eating, dressing, communication and attending to his or her toilet needs. Additionally, the carer should indicate the nature of the child's use of assistive devices. A description of the child's special needs in relation to his or her condition is also requested, such as, use of medication or therapeutic services. In particular, the DLA requests the carer to indicate the child's need for assistance or supervision when performing these tasks (Refer to Appendix D for a summary of section 2 of the DLA).

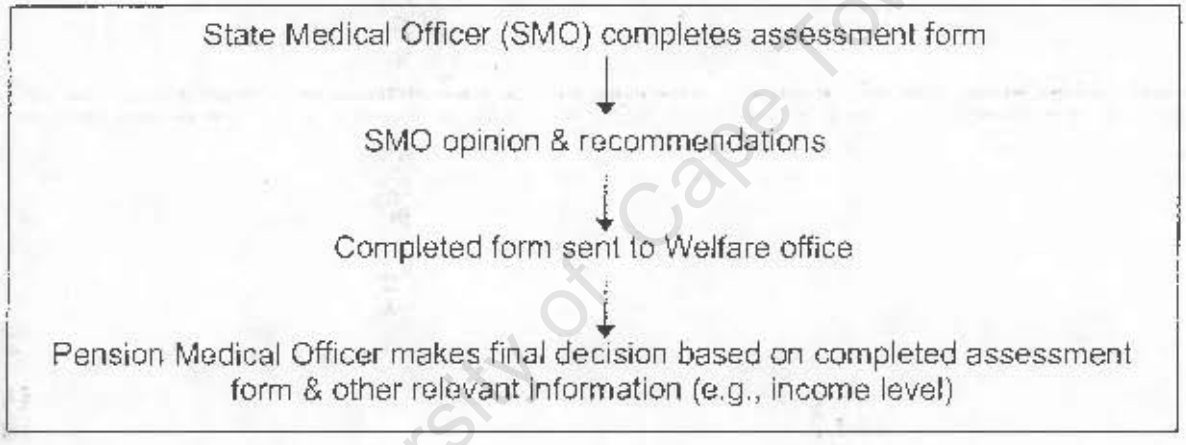
The most significant difference between the DLA and the CDAT is that the CDAT is a benefit *for the carer* of the child with a chronic health condition, while the DLA is a benefit *for the child* with a chronic health condition.

The Care Dependency Grant – Medical Certificate (South Africa)

The South African Care Dependency Grant assessment process and social security context has been referred to in chapter 1 and previously in this chapter. Figure 3 below illustrates the researcher's conceptualisation of the assessment process.

The current South African tool consists of four sections. Section A requires the applicant to provide the child and applicant's biographical details. Section B contains the consent and agreement of a medical practitioner and the applicant to the release of the child's medical details for the grant application.

Figure 3: Assessment Process for the South African Benefit



Section C contains the child's medical information, specifically the results of a medical examination, a diagnosis and prognosis. The State Medical Officer completing the form is asked for his or her opinion and recommendations in relation to the child's level of disablement (severe, mild or not disabled), rehabilitation or special treatment and special education. The Medical Officer is also requested to submit his or her opinion as to whether the child requires permanent home care due to his or her disability.

Section D contains a functional assessment of children aged 4 years. The tool merely states: "Functional Assessment (age: 4 years)" (Care Dependency Grant, 1996; Appendix E). This includes an assessment of the child in the following domains: mobility, self care, communication, psychosocial adjustment and cognitive functioning. The following skills within each domain are assessed:

- *Mobility*: sitting crawling, standing (alone), walking (independently) and running (well co-ordinated);
- *Self Care*: eating, grooming, bathing, dressing, and toiletting;
- *Communication*: comprehension, expression, and speech intelligibility;
- *Psychosocial adjustment*: social interaction and emotional response;
- *Cognitive functioning*: copying, memory and orientation.

(Care Dependency Grant, 1996; Appendix E)

The Medical Officer is requested to submit his or her opinion on the child's ability to function in the mobility and self care domains. For the mobility domain, the Medical Officer indicates "yes" or "no" depending on whether the child can accomplish a particular skill (Care Dependency Grant, 1996: 57; Appendix E). For the self care domain, the child is rated according to his level of dependence on a scale from 1 to 5:

1 = total dependency; 3 = 50% dependency; 5 = independent.

(Care Dependency Grant, 1996: 57; Appendix E)

In the other domains, the Medical Officer is asked to perform certain activities with the child and caregiver and to indicate the child's responses. The child's response to one task or activity is the basis of the assessment for that particular skill, e.g., to assess the child's comprehension ability, the Medical Officer is requested to "Ask the child to fetch the book on the table and to bring it to you." (Care Dependency Grant, 1996: 58; Appendix E).

The Medical Officer is also asked if there is any further information that will contribute to the assessment. Finally, he or she is requested to submit his or her opinion and recommendation as to the kind of care that the child requires:

> Full time care; part time care; whether the child is able to care for him or herself; or whether the child should be referred for further assessment.

(Care Dependency Grant, 1996: 59; Appendix E)

The South African instrument predominantly relies on the judgement of the medical officer completing the form. It consists of open-ended questioning as well

as quantitative measures, particularly in the functional assessment. The functional assessment appears to apply *only* to children who are four years old.

The questions posed in the functional assessment are largely dependent on the child's performance on the day of the assessment, e.g., the measurement for social interaction is "Observe how the child interacts with you, his mother, or other children in the vicinity." (Care Dependency Grant, 1996: 58; Appendix E).

There are no definitions of terms or guidelines for the use of the tool. For example, definitions of the specific eligibility criteria of 'severe disability' and 'permanent home care' are not provided (refer to Appendix E for the South African tool).

Categories of Assessment used in the Three Instruments

The DLA tool and the CDAT have clear categories of needs or indicators that they use as measures of assessment. Both tools use the categories of activities of daily living such as feeding, bathing, walking, amongst other items of assessment. However the type of information elicited within each of the categories are either functional (Australian) or needs related (United Kingdom). A synopsis of these categories and the categories used in the South African tool are presented below in Table 8.

As can be noted from Table 8, there are many shared categories in these tools. It is also evident that the DLA requests more comprehensive information. It not only covers functional categories from a perspective of the child's need for care, but also the child's need for supervision and care in various contexts.

CONCLUSION

Fundamentally, the perceptions of disability and chronic health conditions are a function of the framework or premise that one adopts, as well as related to the purpose of a programme or service. In relation to the ICF's three-pronged definition, one is likely to assume one or a combination of these aspects of disability – the organic level, impairment level or handicap level. Ideally, a holistic approach would embody all three aspects of disability, likened to the non-

categorical approach to chronic health conditions. A holistic approach would also include social and environmental factors and consider the extent of their impact on the individual's functioning.

Table 8: Categories of Assessment in the Three Instruments

Australia	United Kingdom	South Africa
Listening, reading & understanding Talking, writing or signing	Communicating with other people	Communication
Feeding & mealtime skills	Eating & drinking	Self care (eating)
Hygiene & grooming skills	Washing & bathing Help with toilet needs	Self care (grooming & toileting)
Dressing skills	Getting dressed or undressed	Self care (dressing)
Social & community skills	Delay in social skills	Psychosocial adjustment (social interaction)
Hand movement	Delay in physical/sensory skills	
Body Movement	Walking/mobility Waking, getting up & going to bed Movement & co-ordination Moving about indoors	Mobility
Behaviour	Child's mental health	Psychosocial adjustment (emotional response)
Special care needs	Help with medication Help with medical equipment Blackouts, fits, seizures	Special treatment / rehabilitation
	Supervision	Permanent home care
	Delay in learning skills	Cognitive functioning
	Help with therapy	
	When the child is in bed at night	
	Help the child needs on outings	

Secondly, an approach that is not founded or defined by medical diagnosis or perspective would be most beneficial, such as the non-categorical framework. Significantly, the majority of the tools examined in this chapter measure the 'burden' of the child with a chronic health condition on the caregiver, family or broader society. For example, the LAQ measures clinical burden, Life-H measures

personal care, while PEDI measures the caregiver's assistance and modifications. The non-categorical framework identifies the consequence of the condition, including the dependency a child may have on health care or caregiver assistance. This is a vital dimension that should be included in an assessment tool.

All of the tools also consider activities of daily living, though the perspectives vary. Some approach it from the degree of care that a child requires, while others concentrate on the child's ability to perform tasks related to his or her age. However, the limitation of a child's daily functioning as a consequence of the condition is an important consideration.

In particular, social security assessment processes and instruments in South Africa should consider the impact of the condition on the child and the caregiver, as this domain has been sorely neglected. The costs of caring for children with chronic health conditions, whether financial or in other aspects, is a concept that is of utmost importance. The socio-economic conditions and context of individuals living with chronic health conditions should be paramount in any assessment process, given the gross disparities between communities in South Africa.

This kind of approach would be most applicable to the South African scenario. It upholds a rights-based approach, as the individual's needs are paramount in the assessment process. This chapter presented a review of relevant literature pertaining to the social security assessment of children with chronic health conditions. The following chapter describes the research design and methodology adopted in this study.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

The following chapter will present the design and methodology employed and informing the data collection, data capturing and data analysis phases of the study. The hypothesis, instruments used and sample design will also be discussed in this chapter.

DEVELOPMENT OF THE HYPOTHESIS

This study assumed the hypothesis that the Australian instrument and the United Kingdom instrument would more appropriately identify and capture the social assistance needs of children with chronic health conditions in a South African context.

This hypothesis is founded on the belief that the current social assistance assessment tool used in South Africa to assess children with disabilities is inappropriate and limited. One major flaw is that the instrument does not capture or identify the needs of children with chronic illnesses, purely focussing on children with disabilities. As a result of the inadequacies of the tool, the assessors administering the tool are required to rely firmly on their opinions and judgement regarding the child's condition and eligibility for the benefit. To inform the development of an appropriate South African tool, it was determined that a study of existing instruments used in other countries should be conducted.

Following a search for appropriate assessment instruments, the Australian and United Kingdom's tools were found to be fairly appropriate, containing useful indicators and constructs that should capture the additional needs of children with chronic health conditions. Both tools appeared to be more comprehensive, with a broader range of questions that seemed sensitive and appropriate to address the issues not covered in the South African tool.

What is also significant for the purposes of this study is the manner employed to capture or measure the various aspects or implications of a child's condition.

Though a tool may identify a certain aspect or need, whether the extent or type of information is relevant in the South African context is an important consideration.

As a result, it was thus hypothesised that both tools have the capacity to capture and reflect the additional and holistic needs of children with chronic health conditions in a more appropriate manner than the current South African tool.

THE INSTRUMENTS USED IN THE STUDY

The following instruments were applied on a sample of 18 children with a range of chronic health conditions: the United Kingdom's Disability Living Allowance (DLA) claim form, and the Australian Child Disability Assessment Tool (CDAT). Both the CDAT's Treating Health Professional's (THP) questionnaire and the functional assessment completed by the caregiver were used for data collection. Additionally, the caregiver's claim form was also administered. The results and the application process of these tools were compared with the outcome of the current South African tool.

The CDAT, DLA claim form and the current South African tool are described in chapter 2. (The three tools are attached as Appendices A, C and E respectively.)

SAMPLE DESIGN AND SAMPLING METHODS

The target population for this study was children with chronic health conditions attending tertiary health care facilities in the Western Cape. The sample population consisted of 18 children with six types of chronic health conditions attending Red Cross War Memorial Children's Hospital services.

Red Cross Children's Hospital serves the largest number of children requiring tertiary healthcare and offers the widest range of chronic health condition services in the Western Cape, therefore providing a representative sample of the main conditions affecting children. Generally, children who attend the Hospital are between birth and 13 years of age, though the age restriction varies with individual services.

Sampling Technique

The sample size was chosen primarily because of the constraints of this study as a limited dissertation, and as an explorative study that would propose specific recommendations for the further development of a South African tool.

The sampling technique employed in this study combined purposive sampling and convenience sampling. Babbie and Mouton (2001) reflect that interpretive research most often utilises purposive sampling techniques. Purposive sampling was used initially to identify the Hospital services or clinics that served the target population. Hereafter, from the children attending these clinic services, three children representing particular chronic health conditions were conveniently selected to participate in the study.

Out of a list of a range of clinic services that served a broad population of children with chronic health conditions, 6 clinic services were chosen. These were clinics that served children with the following chronic health conditions: HIV/AIDS, cystic fibrosis, developmental disability, cancer, cerebral palsy, and hearing impairment.

These chronic health conditions were chosen primarily as the sample should represent both chronic illness and disability. Secondly, these types were chosen because of their high prevalence rates, and because they were easily accessible at the Red Cross Children's Hospital. From the chronic health conditions selected, three are disability types (cerebral palsy, developmental disability and hearing impairment) and three are chronic illness types (cystic fibrosis, cancer and HIV/AIDS).

Selected Chronic Illnesses

As chronic illness has been excluded from social assistance eligibility in South Africa, the choice of conditions was very important. The impact of chronic illnesses on the lives of children and their families in South Africa are not as well known as for disability. HIV/AIDS was included because of the well known debates and concerns about the care of children who are HIV positive, the costs and access to medical treatment and the resultant cost of care for the caregiver.

Cancer was chosen because it manifests as either a temporary or permanent condition. Again, little is known about the effects of this condition, whether temporary or permanent, on the lives of children in South Africa. Thirdly, cystic fibrosis was chosen as it represents a range of respiratory conditions, including asthma, which is a "...highly prevalent disease in South Africa." (Zar & Weinberg, 2002: 2). Cystic fibrosis is one of the most costly respiratory conditions to treat and manage, particularly the costs of medication and equipment (Beatty, 2002).

Selected Disabilities

Hearing impairment was selected for this study as it represents the only sensory impairment included, and has fairly high prevalence rates. Similarly, cerebral palsy and developmental disability were selected because they are fairly common conditions, thus representing large numbers of children.

DATA COLLECTION METHODS

Permission to conduct the study was obtained from the Provincial Administration of the Western Cape, Department of Health as well as the Heads of Department of each selected clinic.

The two international instruments were administered to the caregivers of the selected group of children i.e., each child's caregiver was interviewed individually on two occasions. The researcher conducted the interviews in English and Afrikaans, where appropriate. An interpreter was available to assist with the caregivers who were Xhosa-speaking.

Access to The Sample

The Hospital services held clinics regularly – for example on a weekly or daily basis, on specific days. The patients attended these clinics at the Hospital, depending on the clinic appointments given to them. The researcher attended the clinics after obtaining permission from the clinic management on the specific days the clinics were held.

At the clinics, the researcher informally approached carers to explain the full details of the study and to obtain their consent to participate. The carers were also assured of confidentiality and anonymity throughout the process, and carers were then asked to complete a consent form (refer to Appendix F).

The first interviews to administer the United Kingdom's tool were then conducted or arrangements were made with the carer to conduct this interview at a suitable time. This procedure was followed until three participants from each type of chronic health condition had been interviewed. Once the initial interview was completed, the researcher made arrangements with the caregiver to conduct the second interview, usually for the following week.

The Data Sets

Thus, data was collected through the application of the two instruments in an interview process. An additional question asked of carers is whether there were any other problems or concerns that the caregiver wanted to discuss that the two instruments had not addressed. Additionally, a State Medical Officer was requested to assess these children's eligibility for the South African grant, based on current legislation.

Data Collected for the United Kingdom's Assessment

The majority of the initial interviews were conducted at the Hospital. Private rooms and spaces were used where available to conduct the interviews. However, this was not always possible, and the researcher was obliged to conduct a few interviews in shared public spaces, such as waiting rooms.

Data Collected for the Australian Assessment

The majority of the second interviews were conducted at the caregivers' homes, as this was more convenient for carers. A few carers preferred to conduct the interview at the hospital, and the researcher then compensated them for the travelling costs. Additionally, a food parcel was given to participants to acknowledge their participation in the study.

The Australian system also uses a second questionnaire that is completed by a THP to help determine eligibility. These questionnaires were given to the children's treating doctors to complete.

Data Collected for the South African Assessment

A third set of data was elicited from an experienced State Medical Officer who has been completing applications for the Care Dependency Grant for many years, and is very familiar with the legislative requirements. The Medical Officer was provided with a profile of each child's condition and circumstances, and asked to determine which children in the sample would be eligible for the Care Dependency Grant based on the present eligibility criteria and legislation.

DATA CAPTURING AND DATA EDITING

The data was recorded on the assessment instruments, for both the United Kingdom and Australian tools. The State Medical Officer provided data pertaining to the South African tool, including the reasons for each child's eligibility or non-eligibility.

As the United Kingdom's instrument contains predominantly qualitative information, and the tool was used predominantly as an interview schedule, the first interview's material was captured and summarised in a short report, capturing the carer's responses to each question in the instrument. The researcher numbered each question in the instrument and then recorded each participant's response to each question. It was therefore easier to compare carer's responses to specific questions. This was not applicable to the Australian tool as it contained predominantly quantitative information.

The next phase of data capturing involved tabulating the responses of both tools according to the questions contained in the instruments. The most pertinent questions were operationalised into categories of a few words or phrases. This was conducted for both instruments, and similar questions in the two instruments were given the same categories. The number of caregiver responses in a particular category according to the type of condition was recorded in these tables.

Additionally, information collected in the interviews that was not a response to a question posed in the instruments was tabulated separately. This was done particularly for the carers' responses to the additional question. Emerging themes were translated into categories and the number of responses within each type of condition was recorded.

DATA ANALYSIS

The primary procedure used to analyse the data was thematic or conceptual content analysis, although this was not always applicable. Content analysis is defined as the examination of "...words or phrases within a wide range of texts... a researcher is able to make inferences about the philosophical assumptions of a writer, a written piece, the audience for which a piece is written..." (Palmquist, 1993 in Babbie & Mouton, 2001: 491).

As this study is concerned with the kind of categories and measurements used in an assessment tool, it was felt that the analysis should particularly consider the content of the instruments, categories of assessment used as well as language and definitions.

Considering the data presented in the tables described above, the researcher analysed the data for similarities, differences and shortfalls within and between the two instruments. Particularly, attention was paid to the categories of assessment used in both tools, the kind of information elicited from each tool and the outcomes of each tool. Additionally, categories derived from the data not collected via the instruments were compared with those identified in the tools and these omissions were considered to be the categories of need relevant to South Africa's particular context.

Determining Eligibility Status

Data collected from each international tool was used to assess the children's eligibility for the respective country's benefit, based on each country's regulations. Additionally, a State Medical Officer was requested to assess these children's eligibility for the South African grant, based on current legislation.

A further step in the analysis of the data incorporated determining the eligibility status of each child, based on the data elicited from the tools. The data from each child's DLA tool was considered in respect of the United Kingdom's eligibility criteria as well as the Decision-Maker's Guide. Based on these criteria and guidelines and the given data, the status of each child related to the United Kingdom's social assistance system was decided.

Similarly, the Australian system has a mandatory scoring regime that is employed to determine children's eligibility for the Carer's Allowance, and through this process each child's eligibility status was determined. Refer to chapter 2 for a detailed description of the scoring process.

To verify the results of this process, the researcher requested that a senior researcher and colleague who is familiar with the child disability field, assist with the scoring and determining of eligibility status for both the Australian and United Kingdom benefits.

The results of this procedure were tabulated, together with the children's eligibility status in relation to the South African grant. The numbers of eligible children within each country's system was calculated and analysed.

LIMITATIONS AND SOURCES OF ERROR

The Test-Retest Method

A shortcoming related to the process of data collection is that the research design resembled the test-retest method, and may have some of the biases and limitations related to this method. As the two tools requested similar information from the participants and used very similar questions (Babbie & Mouton, 2001), the participants may not have given an accurate response at the second interview, as they may have found the questions repetitive and familiar.

The researcher attempted to counter-act the effects of the design by avoiding questions in the second tool that had already been asked in the first tool. The researcher also made the carers aware of this at the beginning of the interview.

Researcher Bias and Selectivity

As is relevant to any research study, an element of bias is present because of the researcher's role in the study and interaction with the participants. The researcher may have unwittingly influenced the participants' responses in a number of ways that may be related to personality traits, or perceived affiliation, for example. Additionally, the researcher may have exercised erroneous selection of data, contributing to a biased representation of the data (Mouton, 2001).

The researcher attempted to limit these effects by being aware of potential biases and by remaining neutral and objective.

Social Desirability Effects

This occurs when the participants do not respond honestly to a question, but rather provides an answer that he or she feels is socially acceptable and appropriate, or will please the researcher (Mouton, 2001). This may have occurred in this study, as a few carers were reluctant to discuss the amount and extent of extra care that they give to their child with a chronic health condition.

To minimise these effects, the researcher explained the purposes and role of the study, encouraging participants to be truthful and ensuring confidentiality.

Availability of Subjects

It should be noted that the researcher experienced problems with obtaining voluntary participants. As the researcher approached carers in the Hospital clinic setting, some carers were apprehensive and suspicious of the study, and did not want to participate. These carers influenced others who may have been interested. This was particularly evident with the nigh profile health conditions, such as HIV/AIDS. Additionally, the researcher included carers who were recipients of the grant, as well as those who were not recipients. This may have influenced the carers' attitudes and perceptions of the study.

There were also delays in conducting the second interviews with some of the carers, as a few carers did not keep their appointments with the researcher. As a result, the data captured in the second interview was different to that captured in the first interview, for one or two children, because of their fluctuating condition.

Therefore, to ensure the full complement of the sample size, the researcher was obliged to find replacements for the carers who no longer desired to conduct the second interview, and minimised the potential bias of the differences in data by acknowledging this in the presentation of data.

Non-probability Sampling

As the sample was selected primarily for purposive reasons and convenience, it is therefore not a representative sample, and the results cannot be generalised to a broader context. Thus, the scope and applicability of the study is limited.

ETHICAL CONSIDERATIONS

The Role of the Researcher

As the content of the instruments and the interview process could potentially elicit sensitive issues for the carers, the researcher was aware that her role as researcher might require her to adopt the techniques and skills of a counsellor. The interviews were thus conducted in a flexible, sensitive manner, so that carers felt comfortable and supported in a non-threatening context. Where appropriate, the researcher offered minimal advice, primarily referring carers to appropriate services for their expressed needs. In particular, where carers had queries regarding grants, the researcher provided the relevant information and advice.

However, because of time constraints on the data collection process, the researcher had a minimal amount of time to build rapport and a trusting relationship with the carers, which may have been elicited more accurate and rich data.

Obtaining the Caregivers' Consent

As the research study is about the South African benefit for children with health conditions, the researcher was acutely aware that caregiver's might participate in the study because they expect to receive the South African grant, or perceive the research process as an application for the grant.

Therefore, when recruiting participants for the study, the researcher explicitly stated that the research study did not involve an application for the Care Dependency Grant, neither would participants receive the grant or any immediate assistance from the State. This information was also clearly stated on the caregiver's consent form (refer to Appendix F).

CONCLUSION

This chapter describes the development and design of this research study, including a discussion about the hypothesis, the instruments used in the study, as well as sampling procedures. Data collection processes are also identified, as well as data capturing and data analysis. Finally, this chapter explores the limitations of the study as well as the major difficulties and ethical considerations encountered in the data collection process. The following chapter presents part 1 of the findings of this study.

CHAPTER 4: PRESENTATION AND DISCUSSION OF FINDINGS (PART 1)

THE SAMPLE AND THEIR ELIGIBILITY STATUS WITHIN THE THREE SOCIAL ASSISTANCE SYSTEMS

Following the administration of the instruments described previously on the sample of 18 children with chronic health conditions, the findings are presented and discussed in this chapter and in chapter 5. In this chapter, the descriptive data of the children and their caregivers are presented followed by a discussion of the outcome of the tools, with reference to the children's eligibility for the respective benefits.

PROFILE OF THE SAMPLE

The Children

Of the 18 children who participated in this study, 11 (61%) were male and 7 (39%) were female. The children's ages ranged from 1 year 5 months to 16 years 8 months, with an average of 5.6 years. One-third (6) of the sample was at 2 years of age, while the median age was 4.7 years. All 18 children have birth certificates, and all are South African citizens. Table 9 represents the distribution of the children's ages.

Table 9: Distribution of the Children's Ages

Age in Years	1 – 5	6 – 10	11 – 15	16 and over
No. of Children	12	3	2	1

Education

Almost half (8) of the sample of children were attending some form of educational facility. These included children attending crèche, pre-school, primary or secondary school. Of the remainder, 3 of the carers reported that their children (1 with developmental disability, 2 with cancer) no longer attended a facility because of financial difficulty. None of the children with cerebral palsy or the children with

cancer was attending any form of educational facility. One child with cerebral palsy is of school-going age (8.3 years), but is not attending an educational facility. Due to his severe disability, he can only attend a special care centre, and there is no space currently available to accommodate him in an affordable centre.

As the children with chronic illnesses have fluctuating health conditions, they may be absent from school, depending on their condition. For some children in the sample, this occurred frequently. Half (4) of the carers of children who were attending educational facilities indicated that they were receiving support from their children's schools, as teachers were understanding of their children's conditions and needs, and provided assistance to their children where necessary.

Health Care Needs

The following section describes the children's health-related needs. Table 10 illustrates the children's health care needs according to the 6 primary health conditions selected for this study.

Table 10: The Health Care Needs of the Children

Needs	HIV/ AIDS	Oncology	Cystic Fibrosis	Hearing Impaired	Developmental Disability	Cerebral Palsy
Multiple condition						
Hospitalisation						
Medication & Equipment						
Treatment						
Therapy						

Key: The shaded areas indicate the children most affected by the health care need

Multiple Health Conditions

As described in the previous chapter, the children in the sample were selected according to their disability or chronic illness type. Of the 18 children selected, one-third (6) had multiple disabilities or illnesses, i.e., the primary health condition as identified by the selected categories, as well as a secondary health condition. These were children with the following primary conditions: 2 children with hearing impairment, 2 with cerebral palsy, and 2 with cystic fibrosis.

Hospitalisation

Considering the 6 categories of health conditions, the children with chronic illnesses (HIV/AIDS, cystic fibrosis and cancer) frequented the hospital more often than the children with disabilities, and spent longer periods in hospital than the children with disabilities. Children with cystic fibrosis and HIV/AIDS frequented the hospital every 2 or 3 months, ranging from a few days in hospital to a few weeks. The children suffering from treatable cancer were hospitalised for the longest periods: 6 months and 18 months and only going home for weekends. The child with non-treatable cancer was required to frequent the hospital every 2 weeks. None of the children were in hospital at the time of the interviews, but were attending hospital services for treatment.

Medication and Equipment

The children's need for assistance with medication was widely acknowledged – 14 (78%) children required their carers to administer or supervise their intake of medication. Children with all six conditions required medication, with all the children with developmental disability, cystic fibrosis and HIV/AIDS requiring medication. The extent of assistance needed was relative to the child's age and functional ability. Where particularly intricate measures and equipment was needed, carers supervised or administered the medicine, as was the case with the cystic fibrosis sufferers.

The children with cystic fibrosis required medication with every meal, while children with cancer consumed about a dozen tablets a day. In addition the children with cystic fibrosis all used some form of breathing apparatus or equipment to assist their respiration on a daily basis. The use of medication and equipment was increased during periods of illness for those with fluctuating health conditions.

Affordability and Accessibility to Treatment

Of the 18 carers, 5 (28%) of the carers acknowledged that the child's medical expenses were an added burden on the finances of the family. These were carers

of children with cerebral palsy, cystic fibrosis and HIV/AIDS. Additionally, travelling to and from hospital placed additional financial strain on some of the carers.

Particularly for children with cystic fibrosis, carers mentioned that the costs of medical care are exorbitant. The costs of medication alone can amount to R90 000 per annum. Additionally, the equipment used, such as ventilators, costs in the region of R35 000 per item. As these children required hospitalisation for a few weeks every few months, the costs of hospitalisation were also high. For carers who benefited from medical aid or whose children were subsidised by the State, the financial pressure was lightened. However, for carers who could not afford the necessary medical care their children required, these children's states of health were adversely affected. Carers also reported that they could not access the most effective forms of medication for their children because it was too expensive. Additionally, a few carers found that alternative medicines, such as homeopathic products, were helping their children. However, these products were reportedly also costly.

Similarly, the carers of children with HIV/AIDS described their concerns about the lack of accessibility to affordable treatment that could improve both the carer and child's health conditions. These carers would like access to anti-retroviral treatment and requested that the prices be reduced or that government subsidise the cost of this medication. Carers reported that the cost of this medication amounted to roughly R800 per month.

Of the 18 children, 5 (28%) are receiving treatment for epilepsy as well. When going out during the day or night, the children requiring daily medication and treatment would need to carry their medication and equipment along with them.

Therapy

A high percentage of children (11) receive therapeutic intervention such as physiotherapy. The amount of therapy and frequency of sessions at the hospital varies, depending on the child's condition. Many of the children also receive home programmes, where the carer is required to conduct therapy with the child. Of

these children, 7 (64%) were children with disabilities. Children across all the health conditions except HIV/AIDS were receiving therapy. The frequency of attendance at the therapy sessions varies depending on the disability or illness type. Some attend on a weekly basis, while others attend every three months.

Behaviour and Emotional Problems

Half of the children (9) were identified as having behavioural and emotional difficulties by their carers. The majority of these children (5) were children with chronic illnesses. Behavioural difficulties such as frequent tantrums and aggression were more common in children with disabilities, such as the children with developmental disability. These difficulties may be related to the child's condition, e.g., hyperactivity and aggressive behaviour are quite common in children with developmental delays. Most of the children with chronic illnesses often became withdrawn, unsociable, and some became aggressive during periods of poor health, impacting on their family relations and friendships.

Activities of Daily Living

For most of the activities of daily living, the children with chronic illnesses generally functioned at an age-appropriate level. However, it was during periods of poor health that they were likely to be unable to accomplish these tasks satisfactorily. As a result these children's functioning fluctuated, dependant on their state of health. It was also noted that these children's development regressed during periods of poor health, for example, the children with cancer could no longer walk, feed themselves or attend to their toileting needs during periods of poor health, which they were able to accomplish before their ill health.

Mobility

Half (9) of the children were identified as having mobility problems, with 7 (78%) of these children suffering from a disability, e.g., cerebral palsy. Children with cancer and cystic fibrosis were identified as having mobility difficulties during periods of poor health. As a result of the mobility problems, these children required varying

degrees of supervision, depending on the severity and duration of the mobility difficulties.

The children with constant mobility difficulties, such as the children with cerebral palsy, required daily and continuous supervision, as well as requiring physical support to sit, stand or walk. They also required additional means of support such as a buggy, similar to a pushcart, or special chairs. Using such devices and equipment posed problems for some carers, particularly when taking the child outside of the home. These children required considerable assistance when travelling or going on outings.

Communication

Of the 18 children, 12 (67%) were identified as having communication difficulties. The majority (8) of these children were those with disabilities - mainly children with hearing impairments, who made use of hearing aids, and children with cerebral palsy. These children required assistance, whether by sign language or gesturing, in helping them to understand communication from others, and helping others to understand their communication.

Personal Hygiene and Self-Care

More than half (11) of the children had difficulties attending to their personal hygiene and self-care activities, such as bathing and dressing. Consistently, children with disabilities required help with these tasks, as they were unable to accomplish these tasks on their own due to physical impairment or low intellectual functioning. Children with chronic illnesses had difficulties accomplishing these tasks during periods of poor health, or because the child's development was delayed due to the illness. Children with cancer in particular were physically unable to accomplish such tasks during periods of poor health.

Eating and Drinking

Similarly with eating and drinking, the majority of children with disabilities required assistance, particularly children with cerebral palsy. Children with chronic illnesses were affected during periods of poor health.

In general, children with chronic illnesses needed to pay particular attention to their diets, and when severely ill, they required nasogastric or syringe feeding. With regard to nutrient intake, 2 children with cystic fibrosis required their bodily excretions monitored daily as an indication of their need for enzymes.

Carers also highlighted that their children required more food than their peers, or required special foods that were expensive. To maintain their children's health condition, carers needed to provide nutritious foods regularly, and for many of them this was costly, and required the resources of time, attention and effort.

Toileting

With regards to toileting needs, the majority (6) of the children with disabilities required assistance. This ranged from the carer periodically attending to the child's needs, as he or she is unable to communicate, to the child requiring assistance when using the toilet. Children using the nappy required to be changed several times a day and during the night.

With regards to children with chronic illnesses, children with cystic fibrosis and children with cancer were mainly affected. Of these children, 67% (4) required assistance, such as needing to be carried to the toilet because of physical weakness. Some of these children suffered from diarrhoea and enuresis during the day and night, and lost control of their bowel and bladder functions. Most of these children required such assistance during periods of poor health. However one child required continuous attention as she has poor control of her bowel and bladder functions and soils her clothing daily.

Assistance Required while In Bed and During the Night

Of the 18 children, 7 (39%) had difficulties with waking, getting up or going to bed. The majority of these children were children with disabilities. These children required physical assistance to get in or out of bed, or when lying down. Children with chronic illnesses mainly had difficulties waking and getting up, e.g., the children with cystic fibrosis required more sleep than their peers, or were too physically weak to get out of bed, such as the children with cancer.

More children with chronic illnesses required attention during the night than the children with disabilities. These children became ill frequently during the night, and needed to be attended to as well as having their bedclothes changed. The children with cystic fibrosis may have required therapy during the night if they were coughing excessively. In comparison, the children with disabilities who required attention were those who needed nappy changes or to be turned from side to side while in bed. Some of these children required some form of comfort, such as the presence of the carer, to fall asleep.

In addition to the assistance required with activities of daily living, some of these children required supervision. Some of the carers also discussed the impact of providing care of their children.

Supervision and Care

One-third (6) of the children were identified as requiring supervision mainly during the day and some at night, due to their disability or illness. The majority of these children were children with communication, speech, behaviour or learning difficulties. These children required supervision to ensure that they were not a danger to themselves or to others because of their inability to perform certain functions, such as hearing, talking or walking. One child with cystic fibrosis required supervision at night because of her struggle to breathe.

Many of these children required continuous care, particularly the children severely affected by the disability or illness such as those with cerebral palsy or cystic fibrosis. The carers of these children were often over-burdened and drained due to

the amount of care the child required. 2 carers indicated that they were fully occupied by caring for these children, and that assistance with their child's care would be welcomed, as it would provide them with some relief. One carer reported that she was considering placing her child in a residential care facility as a result of the high degree of care her child required.

In summary, all of these children had supervision and care requirements, as they all required medical treatment and assistance with activities of daily living. The degree of care required varied dependent on the individual child's health status and type of condition. Most of the children with chronic illnesses had a greater need for medical care than the children with disabilities. In addition, children with chronic illnesses have greater attention requirements with eating, and during the night.

However, a larger percentage of the children with disabilities required regular therapy than the children with chronic illnesses. Children with disabilities had greater mobility, communication and toileting needs, as well as the need for assistance while in bed. Children with disabilities also required more supervision during the day.

The Carers

The following section presents the data elicited from the interviews related to the carers' descriptive data and information pertaining to their households. The second section indicates the carers' responses to the additional question about their problems and concerns.

The carers interviewed in this study were all the primary caregivers of the children selected, and all were female. A large majority (15) of the carers reside in low socio-economic communities such as Khayelitsha, Delfdt and Atlantis. Of the remaining 3, 2 carers reside in affluent communities, and 1 carer lives with her employer in a wealthy community. Half (9) of the carers indicated that their household income was a huge factor limiting their ability to care for their children. This is discussed later in the chapter.

Most of the carers (15) indicated that they come from non-English speaking backgrounds. All of the carers have identity documents. The carer's ages range from 23 years to 59 years, with an average age of 33.2 years and a median of 34 years. Table 11 below illustrates the distribution of the carer's ages.

As can be seen from the table, the majority (10) of the sample falls between the age of 23 years and 34 years. However, it is most interesting that almost half (8) of the sample were in the age group of 35 to 59 years. As the majority of the carers resided in impoverished communities and was relatively young, it is concerning that they are primary caregivers of children with special needs. Only 2 carers indicated that they were involved in volunteer work or training. The rest are either employed or are unemployed – details relating to the carers employment status was not elicited in this study.

Table 11: Distribution of Carer's Ages

Age in Years	23 – 28	29 – 34	35 – 40	41 – 59
No. of Carers	5	5	4	4

Relationship to the Child

Of the 18 carers interviewed, 15 (83%) carers were the biological mothers of the child concerned, 1 was the 41 year-old grandmother of the child, one a foster-mother (59 years) and the other was the child's older sister (25 years). The grandmother was caring for her grandchild with leukaemia, while the sister was caring for her sibling who had HIV infection, as their mother had died from AIDS. The foster-mother had been caring for the child with cerebral palsy for 3 years, since he was 9 months old. All of the carers were caring for one child with a disability, and all personally provided care to the child concerned. All of the carers had cared for the child concerned for more than one year.

Family Structure

Of the 18 carers, 7 (39%) were single, 10 (56%) were married, and one was separated from her husband. Of the 18 carers, 5 (28%) were living with extended families, one was living with her employer and a single carer was living alone. The

remaining 11 (61%) were living with their husbands, children and/or grandchildren. All of the children concerned are living in the same household as their carer.

Social Security Benefits Received

Of the 18 carers, 3 (17%) were receiving the Child Support Grant (CSG), whereas 6 (33%) carers were receiving the Care Dependency Grant (CDG). The foster-mother is receiving the Foster Care Grant (FCG). The amounts of the grants are R130, R630 and R450, respectively. Nearly half (8) of the carers specifically mentioned the role of grants in the family's income. Table 12 below illustrates the carer's perspectives of the grants.

Table 12: Carer's Views of the Three Children's Grants

Role of the Grant	Foster Care Grant	Care Dependency Grant	Child Support Grant
Significant Difference		38%	
Insufficient	13%	25%	38%
Needed for Health Care		25%	

Of these carers, 3 (38%) mentioned that the Care Dependency Grant made a significant difference in the family's ability to cope financially. For one of these carers, the CDG was the only form of income for the family. However, 2 carers felt that the CDG was insufficient. Similarly, carers who received the FCG and CSG indicated that the grants provided for a minimal portion of the child's needs, and should be increased. Of the carers of children with chronic illnesses, 2 reported that financial assistance would have been helpful during their children's periods of poor health, but their children were not eligible for the CDG.

Only one carer was a member of a household where a recipient of the State Old Age Pension also resided.

Utilisation of Health Care Services

Significantly, when discussing their children's use of health care services, 10 (56%) carers, the majority being carers of children with chronic illnesses, indicated

that they utilised only tertiary level health care services instead of primary level health care. These carers mainly frequented Red Cross Children's Hospital services, where their children were attended to by predominantly one specialist. One carer only utilised tertiary level care because there were no primary health care facilities in her community that could treat her child's condition. Of the 18 carers, 5 (28%) carers indicated that they utilised both primary and traditional medicine as well as tertiary level services, while 3 (17%) indicated that they utilised both private and tertiary health care services. Carers were also grateful for the support that they received from medical personnel at the tertiary hospital.

Additional Problems and Concerns Indicated by the Carers

Household Income

Half (9) of the carers indicated that their household's income impacted greatly on the carers' ability to care and provide for the child concerned. Two-thirds (6) of these carers indicated that no one in the household was receiving a stable income. The remaining one-third (3) of carers identified one steady income-earner in their households.

One-third of these carers also reported that there was often no food in their households as a result of the family's financial situation. Some of these carers borrowed food from others to feed their children. One carer also mentioned that she was unable to purchase the necessities her child required for school or provide for his transport costs to school. Another carer mentioned that she could not afford her child's school fees, while another highlighted that the house they were living in could not accommodate the entire family, therefore some of her family and older children were living elsewhere.

Significantly, two-thirds (6) of these carers were caring for children with chronic illnesses, and thus the family's ability to provide for the child concerned seem to have a greater impact on the carers of children with chronic illness.

A few carers also mentioned that they have other dependants to care for besides the child concerned. One carer also reported that she is providing for her own

children as well as the children of extended family and that the cost of providing food, clothing and schooling is great.

The Financial Impact of Providing Care

Two-thirds (12) of the carers indicated that they were experiencing financial difficulty because of the related costs of caring for their children. Nearly half of these carers (5) were struggling to provide the basic necessities for their families. The majority (8) of these carers acknowledged that the costs of caring for a child with a chronic health condition was great, as they required extra or special food, medication, travelling costs, clothing, nappies and school fees. The carers of children with chronic illnesses, particularly cystic fibrosis and cancer, reported that the additional needs of their children are a heavy financial burden on the family.

Travelling to Hospital

Half (9) of the carers specifically highlighted their difficulties with travelling to the hospital to attend therapy sessions or doctor's appointments. A large majority (7) of these carers had problems with the costs of travelling to and from the hospital, some of who frequented the hospital on a weekly basis. Some of these carers found ways of obtaining finances, such as borrowing from neighbours when they were unable to afford the costs. If this were not possible, the carer would forego the child's hospital appointment.

An additional factor was the distance that the carer and child needed to travel, as the majority of carers did not live in close proximity to the hospital. Some travelled from the outskirts of Cape Town such as Atlantis and Malmesbury. Related to this factor was the poor accessibility of public transport facilities from rural areas.

Additionally some carers of children with mobility problems needed to transport the child using a buggy or other form of equipment, to the hospital. This created problems for the carer who used public transport, as she would be charged an additional fee for the transportation of the special aid. The other alternative was that the carer was forced to carry the child to the hospital.

Family Support

Of the 18 carers, 10 (56%) mentioned family support as a significant factor that impacted on the carers' ability to provide quality care for their children. Only one-third (6) of the sample of carers indicated that they were receiving support from their families, whether this is financial, emotional or practical assistance, and only 1 of these carers reported that the child's father was providing financial support. Almost half (4) of the 10 carers indicated that they were receiving no support of any kind from their extended family. Some of these carers acknowledged that they felt their families did not understand the child's condition and therefore could not offer support. Particularly for the children with HIV/AIDS, the carers had not informed family members about the child's health condition because of the stigma attached, and fear of the consequences.

It is interesting that 6 (60%) carers of children with chronic illness highlighted family support as a factor in comparison to 4 (40%) carers of children with disabilities. It may be that the emotional impact on the carers of children with chronic illness is greater than for carers of children with disabilities.

Risks and Losses to the Family

Almost half (8) of the sample of carers indicated that they had experienced certain risks or losses as a result of caring for a child with a chronic health condition.

The large majority (6) of these carers indicated that they had experienced risks or losses with regards to their employment. Of these carers, one-third (2) reported that they were obliged to resign from their job because of their child's need for constant care. Another third (2) of these carers reported that their frequent absences from work as a consequence of taking their children to hospital created problems at their workplace. One carer had experienced dismissal from her job, and another had come close to dismissal, because of their frequent visits to hospital when their children had been hospitalised. These findings suggest that carers of children with chronic health conditions are vulnerable to job loss and unemployment as a result of providing care to their children.

The other 2 carers highlighted that they had almost lost their houses as a result of their financial position after paying for the treatment and medical costs of their child. One carer also highlighted that the child's father had abandoned the family after receiving the news of the child's health condition.

Significantly, the vast majority (7) of the carers who mentioned these risks and losses are carers of children with chronic illnesses. This indicates that the financial strain and vulnerability to financial loss may be greater for the families of children with chronic illness than the children with disabilities. Thus, families of children with chronic health conditions may be at greater risk of loss of income and assets as a result of providing appropriate medical and other care for their children. Providing care for children with chronic health conditions may plunge families into greater poverty.

Emotional Impact

One-third (6) of the carers highlighted that the child's health condition was an emotional strain on the child, carer and family. The carer's mentioned that they frequently felt depressed and burdened because of the child's health condition and when considering the child's future. An essential factor that increased the emotional strain was the financial pressure that carers experienced as a result of their child's health condition.

Significantly, only carers of children with cystic fibrosis, cancer and HIV/AIDS mentioned the emotional impact of caring for their children. According to these carers, the children's periods of poor health were a traumatic experience that impacted on the entire family. Some carers mentioned that the child's illness often resulted in disruption and separation of family members.

For the children who were at an age where they were able to understand, they had many questions and themselves experienced trauma, anxiety and fear. Carers mentioned that the children required counselling and support as a result.

The following section presents the outcomes of the tools and the reasons for the exclusions and inclusions of the children for eligibility.

ELIGIBILITY FOR BENEFITS

After determining the eligibility status of each child according to the eligibility criteria of each country, the following outcomes were found. Of the 18 children in the sample, less than half (8) of the children were eligible for the South African grant, the Care Dependency Grant. The large majority (17) of the children were eligible for the United Kingdom grant, the Disability Living Allowance, while 16 (89%) children were eligible for the Australian grant, the Carer's Allowance.

The eligibility of the children within their disability or chronic illness type is represented below in Table 13. The figures indicate the numbers and percentages of children in that category that were eligible for the respective benefits. Note that the children eligible for the United Kingdom's allowance were eligible for any rate of the mobility and/or care component.

Table 13: Eligibility by Type of Health Condition

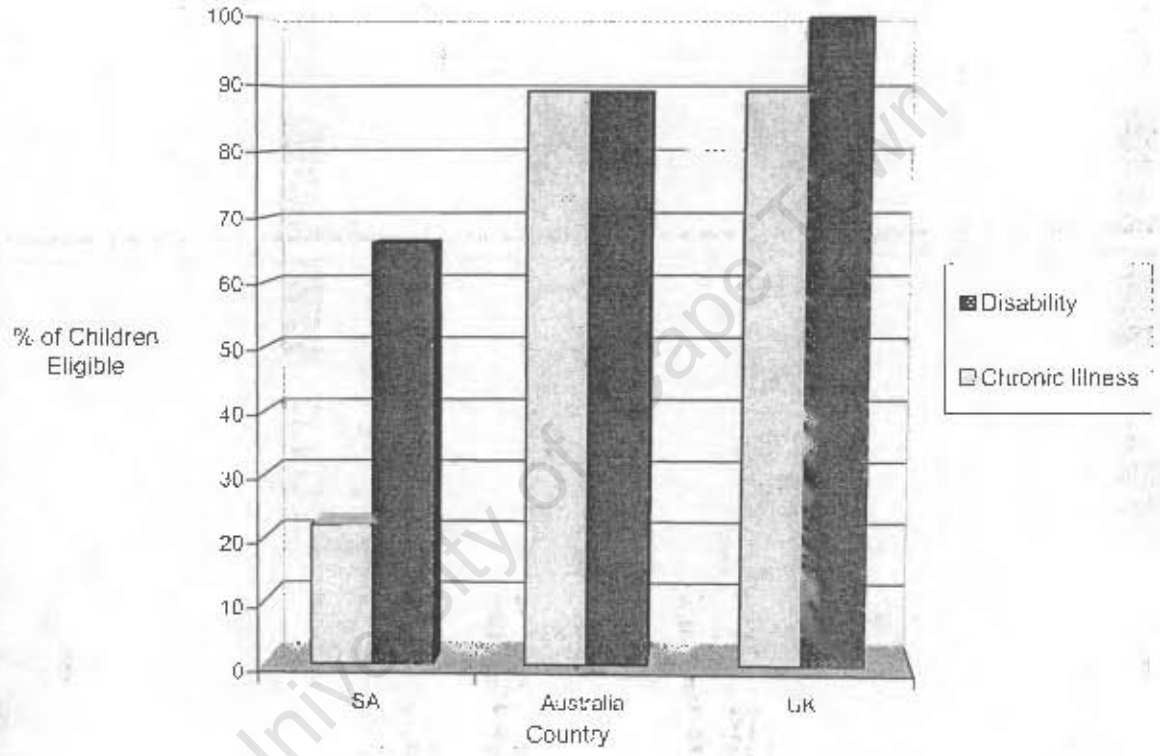
Category	South Africa		United Kingdom		Australia	
	No.	%	No.	%	No.	%
Cerebral Palsy	3		3		3	
Developmental Disability	0		3		2	
Hearing Impairment	3		3		3	
DISABILITY TOTAL	**6**	**67**	**9**	**100**	**8**	**89**
Cystic Fibrosis	1		2		2	
Oncology	1		3		3	
HIV/AIDS	0		3		3	
CHRONIC ILLNESS TOTAL	**2**	**22**	**8**	**89**	**8**	**89**
TOTAL	**8**	**44**	**17**	**94**	**16**	**89**

Significantly, the South African system excluded the majority (10) of the children in this sample from accessing the South African grant, most (7) of who are children with chronic illnesses. None of the children with HIV/AIDS are eligible for the grant - only 1 child with cystic fibrosis, and 1 child with cancer, qualified for the grant. It is also significant that none of the children with developmental disabilities were eligible for the grant. Applying the legislated criteria rigorously, the children with

cystic fibrosis and cancer should not have been included as eligible for the Care Dependency Grant. These children are not physically or intellectually disabled, and do not require permanent home care.

Figure 4 below represents the number of children with disabilities who proved eligible in each country, in comparison to the number of children with chronic illnesses who qualified for the respective grants.

Figure 4: Percentage of Children Eligible across Chronic Health Conditions



It is apparent that the South African social assistance programme minimally provides for children with chronic illnesses. It is also significant that the United Kingdom provides for the full quota of children with disabilities (9), while Australia is close to this by providing for 8 (89%) of the 9 children.

The United Kingdom and the Australian systems excluded only one of the children with chronic illnesses. Additionally, the Australian system had also denied a child with a developmental disability from accessing their benefit. The reasons for these exclusions are tabulated below in Table 14.

The South African grant system clearly discriminated against children with chronic illnesses, children with temporary health conditions and children with mild and moderate disability. When considering the Australian system, the child who did not meet the requirements because his CDAT score was too low, was a child whose functioning was fairly age-appropriate in most skill areas, and thus was not captured as having an adequate functional deficit to qualify for the Carer's Allowance. This child was, however, eligible for the Health Care Card, as his care and attention needs exceeded 14 hours per week.

Table 14: Reasons for Exclusions

Category	South African	United Kingdom	Australian
Developmental Disability	Disability is not severe		Child does not have a recognised disability & does not score adequately on the CDAT. He therefore does not satisfy the requirements
HIV/AIDS	Condition is not yet disabling		
Oncology	Condition is temporary and children required lengthy stays in hospital		
Cystic Fibrosis	Condition is not yet disabling	Child does not satisfy the age requirements	Child does not satisfy the age requirements

The child who did not meet the age requirements of the Australian and UK systems because he was older than 16 years, would have been eligible within both countries' systems based solely on his health condition.

Eligibility Within Each Country

United Kingdom (UK)

As described in chapter 2, the United Kingdom has two components to its benefit, and each component has differential rates depending on the child's particular needs. The results of the amount of children from this sample who qualified for these respective rates are presented in Table 15 below.

Significantly, 5 (28%) additional children would have qualified for the mobility component based on their mobility difficulties, but they did not meet the age requirements. The mobility criteria applied only to children aged 3 years and older. These were children with hearing impairment (2), cerebral palsy (1), and cancer (2).

Table 15: Children who Qualified based on the United Kingdom's System

Type of Condition	Care Component	Mobility Component
HIV/AIDS	1 – higher rate 2 – lower rate	
Cystic Fibrosis	2 – higher rate (automatic)	
Cancer	2 – higher rate 1 – lower rate	
Developmental Disability	1 – higher rate 2 – middle rate	1 – lower rate
Hearing Impairment	2 – middle rate 1 – higher rate	
Cerebral Palsy	1 – middle rate 2 – higher rate	2 – higher rate

It is also very significant that all 17 (100%) children who were eligible for the allowance had care needs, the majority (9) of them requiring the higher rate of the care component. Of the 17 children, 5 (29%) were awarded the middle rate, and 3 (18%) were awarded the lower rate of care. It thus appears that the UK tool is sufficiently sensitive to capture these children's need for care.

If all the children had met the age requirement, almost half (8) of the children would have qualified for the mobility component of the tool, also indicating the tool's sensitivity in identifying this need. As indicated in the profile of the sample, 50% of the carers had indicated that their children had mobility problems.

It is also important to note that the children with chronic illnesses' need for care were adequately reflected by the United Kingdom's tool, as most of them were identified as requiring the higher rate.

Australia

The children eligible based on the Australian tool are remarkably similar to those eligible based on the UK tool. This is very significant, as these tools use very

different measures and methods of assessment. With the exception of one child, the Australian tool found the same children eligible based on their system as the UK tool. Irrespective of employing very different measures and methods, both tools qualified the same children for their respective benefits. A synopsis of the results from the Australian instrument is illustrated below in Table 16.

Table 16: Children who Qualified based on the Australian System

Category	Requirements
HIV/AIDS	3 – recognised disability (automatic)
Cystic Fibrosis	2 – CDAT scores greater than 1
Cancer	3 – recognised disability (automatic)
Developmental Disability	1 – recognised disability (automatic) 1 – CDAT score greater than 1
Hearing Impairment	3 – recognised disability (automatic)
Cerebral Palsy	3 – recognised disability (automatic)

Identified Disability and Chronic Illnesses

Significantly, children in 5 categories proved eligible for the Australian benefit because they were identified as having a recognised disability, as indicated in the doctor's report. As described in previous chapters, the Australian system has identified particular health conditions that receive automatic qualification for the benefit. It is assumed that children who have these conditions would always obtain less than age-appropriate scores in the domains contained in the CDAT, and thus obtain the qualifying score.

All 3 children with cerebral palsy and the 3 children with hearing impairments were identified, as well as the child with intellectual disability. The list of recognised disabilities thus appears to cater for a wide range of disabilities. It is also interesting that the child with a developmental disability obtained a qualifying score on the CDAT, particularly in terms of the functional items. This is significant, as this child has a marked expressive language delay, and thus the CDAT is sufficiently sensitive to identify and capture a child who is greatly affected in one functional area.

Almost half (6) of the children who were identified with a recognised disability are children with chronic illnesses. It is significant that chronic illnesses are included in

Australia's list of recognised disabilities. The other 2 children with chronic illnesses were found eligible based on their CDAT scores.

Weighting of Special Care Needs

Significantly, the "Special care needs" section of the CDAT is given more weight than the other categories, which is the reason that the children with cystic fibrosis were able to obtain the qualifying score (Carer Allowance: 8, refer to Appendix A). This indicates that the Australian system does effectively identify the needs of children with high care needs due to chronic illnesses, particularly by the insertion of the special care needs category, which carries greater weighting than the functional categories.

South Africa

As described in the previous chapter, only 8 (44%) of the children in the sample were found eligible under the South African system, i.e. less than half of the sample was eligible for the grant. Only 2 are children with a chronic illness, i.e., 11% of the full sample of children. Table 17 below presents a summary of the children who are eligible.

Table 17: Children who Qualified based on the South African System

Category	Requirements Satisfied
Cystic Fibrosis	1 – severe, permanent condition, resulting in physical disablement
Oncology	1 – severe, permanent condition, requiring life-long treatment
Hearing Impairment	3 – severe and permanent disability
Cerebral Palsy	3 – severe, permanent disability requiring total care

Interestingly, the child with cystic fibrosis excluded by the Australian and United Kingdom systems on the basis of age was eligible under the South African system, as the system caters for children until the age of 18 years. However, this child who has experienced 16 years of living with the illness, would only be able to access the grant now, as the illness has reached a stage where it has become disabling. At this late stage, the grant could do very little to enhance the quality of life for this child or to prevent the illness from worsening.

Significantly, the only child with cancer who was deemed eligible has a non-treatable condition, as opposed to the other two children who had treatable conditions. He presently requires frequent medical treatment, and would require treatment the remainder of his life. However, the condition has not yet reached the stage of becoming disabling.

The children with hearing impairment and cerebral palsy were eligible for the grant, on the basis of their conditions being permanent, severe disabilities. It is also noted that the children with cerebral palsy were requiring total or permanent care, indicating that they would need full-time care on a daily basis.

It should be noted that these conditions for eligibility were not adequately defined or measured in the South African tool. The medical officer completing the instrument is requested to provide his or her opinion as to whether the child has a severe disability that is permanent and requiring permanent home-care.

If another medical officer was requested to offer his or her opinion about the children in this sample, the results might have been very different, highlighting the subjective nature of the assessment tool because of unclear definitions and guidelines. It is evident that the medical officer's opinion in the current South African assessment tool is a central factor contributing to eligibility determination – the functional measures and other components of the tool are largely irrelevant and inappropriate.

Need For Care As A Measure Of Eligibility

The following section describes the United Kingdom's rating of need for care - lower, middle or higher, and discusses the rates the children were awarded in relation to their eligibility status for each country. The analysis considers the children who were found eligible based on the three country's systems in terms of the UK rate of care each child was awarded. Figure 5 below illustrates the children eligible within each country's system and the respective rates of care they were awarded.

Figure 5: Children Eligible Within the 3 Countries and Their UK Rate of Care

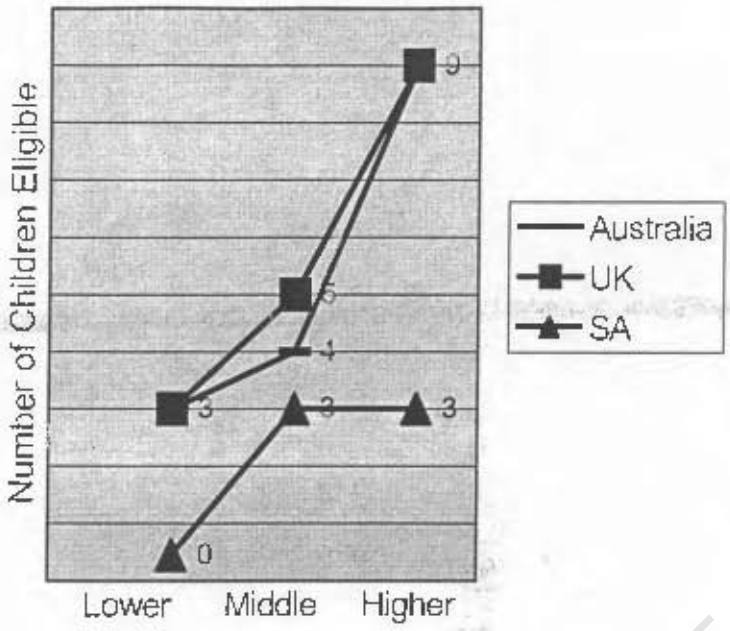


Figure 5 illustrates that the children eligible based on the Australian (16) system when compared with the UK rate of care they were awarded, had been awarded similar rates of care as those eligible based on the UK system. Of the 16 children eligible based on the Australian system, 9 (56%) were awarded the higher rate of care, 4 (25%) were awarded the middle rate, and 3 (19%) were awarded the lower rate of care.

In contrast, the comparable figures for South Africa reveal that 3 of the 8 children eligible for the South African benefit were awarded the UK's higher rate of care, while another 3 were awarded the middle rate of care. None of the children eligible based on South Africa's system have been awarded the UK's lower rate of care – i.e., the children who required care due to their condition, for significant parts of the day or night, were not eligible for the South African grant. This confirms that the South African system does not cater for children who are suffering from less severe or non-permanent health conditions, whereas the United Kingdom and Australia provides some measure of assistance for these children.

CONCLUSION

This chapter presented and discussed the findings of this study in relation to the children and caregiver's needs and experiences. Secondly, the eligibility status of the children based on the Australian, United Kingdom's and South African social assistance systems and instruments are compared and examined. The following chapter presents and discusses an analysis of the tools, considering the children's circumstances and respective eligibility awarded. Pertinent issues relevant to the South African context are also discussed.

CHAPTER 5: PRESENTATION AND DISCUSSION OF FINDINGS (PART 2)

AN ANALYSIS OF THE INSTRUMENTS AND CONSIDERATION OF THEIR RELEVANCE TO THE SOUTH AFRICAN CONTEXT

This chapter presents and discusses an analysis of the tools in relation to pertinent factors, specifically addressing the applicability of the tools for the South African context. The tools are analysed with reference to the descriptive data of the sample and their eligibility outcomes described in chapter 4. This chapter also interprets these findings, considering the literature discussed in chapter 2, and examines the data in light of confirmations and deviations. Finally, this chapter presents the significance of these findings.

ANALYSIS OF THE INSTRUMENTS

Considering the outcomes presented in chapter 4, it is important to understand the reasons for the varied or similar performances by the tools. The following section analyses the actual instruments, highlighting characteristics of the United Kingdom and Australian tools that are both advantageous and disadvantageous. In particular, the use and applicability of these tools in the South African context is discussed.

Type of Information Requested

Questions that were common to both instruments were questions on gender, child's age, caregivers' age, caregiver's relationship to the child and details about the child's receipt of other benefits. Other areas of commonality are details of a spouse or partner, type of illness or disability, permanent residency, hospitalisation and residential care.

However, the amount of detail and phrasing of the specific questions vary in each instrument. From a comparison of the type of information elicited from the respective instruments, it is evident that the DLA elicits more qualitative and

descriptive data. For example, the question on hospitalisation elicits a 'yes' or 'no' response in the CDAT tool, while the DLA tool requests information about previous and current hospitalisation. Details about the length of stay are also requested. Similarly, details about spouses are more descriptive based on the United Kingdom's instrument than on the Australian instrument. The majority of the information collected about the children and carers in the previous section was elicited from the application of the DLA instrument.

Information exclusive to the DLA were questions regarding the child's education, the family's receipt of welfare benefits, medical care and medication, as well as the identification of another informant. Information that was exclusive to the Australian form was details about marital status, and the carer's involvement in volunteer work or training. The Australian claim form seeks more detail about the conditions of care, i.e., whether the carer has more than one child with a disability in his or her care, whether the carer personally provides daily care of the child, and whether the child has been cared for by this carer for longer than one year. Another piece of information sought is the child's first language, and whether the child and carer live at the same address.

A huge advantage of the DLA is that the final section of the tool contains an open-ended question, requesting the respondent to contribute additional information about the child's condition and it's impact that was not covered by the previous questions. This is a very useful section, and many carer's made use of the opportunity to discuss other issues and concerns. An additional advantage in both instruments is the inclusion of payment details, in relation to the carer's receipt of the regular benefit.

As described in chapters 1 and 2, the current South African tool requests purely medical information about the child from a health professional. However, it is difficult for the Medical Officer conducting the assessment to offer reliable judgments on the severity of the child's condition, or to make recommendations for the care needs of the child without guidelines on what constitutes severe disability or appropriate assessment measures.

Methods of Assessment

Each instrument contains a section requesting information about the child's functional abilities. However, the approaches of the international tools are very different: the DLA tool elicits information about how the child's health condition affects the child's daily functioning, while the CDAT focuses on the child's functional ability in relation to his or her age. For example, a child with cerebral palsy who needs assistance with toileting is represented in the CDAT, as "Child cannot do any of the things listed above." (Carer Allowance: 4, Appendix A). However in the DLA instrument the response acknowledges the carer's role of changing the child's nappy several times a day and during the night.

The most significant difference in the type of data elicited is that the DLA tool specifically requests and allows for information about the carer's role – it even requests specific detail about how much time, and how often, the carer spends on a specific activity to assist or supervise the child. This type of information is largely omitted in the CDAT, as this tool has an emphasis on whether the child can or cannot perform age-related activities. The kinds of assessment confirm that the DLA tool is specifically concerned with qualitative, descriptive data while the CDAT is interested in a quantitative measure of the child's functioning.

The DLA instrument allows the respondent to provide an overview of the child's health condition. Through these questions addressing a range of health conditions, one is able to identify the status of the child's health in the carer's perspective. The CDAT does not provide such an overview – the structure of the instrument provides one with a fragmented portrayal of the child, as it identifies the child's level of functioning in specific skill areas (e.g. dressing skills, hand movement). The CDAT excludes questions requesting information about the child's holistic functioning that would provide a picture of the child's overall functioning and well being. Secondly, these questions allow secondary conditions to be captured, which is very important when assessing children with multiple health conditions. This information is not captured in the Australian CDAT, but in the THP's tool.

However, the CDAT does elicit some responses, which may not have been acknowledged in the DLA tool. It requires the respondent to consider a variety of options and scenarios, and then to indicate the options most relevant to the child. As a result, the respondent may identify behaviours and abilities that may not have been identified through an open-ended question requesting descriptive information. An example is a child with hearing-impairment who has behaviour difficulties, was not identified as having problematic behaviour through the DLA tool. However, the specific phrase in the CDAT reflecting the child's behaviour made it possible for the carer to identify his behaviour. Conversely, the choice of a few options to describe a child's functioning can be restrictive, perhaps forcing a response that does not accurately describe the child's ability.

What was common in the application of the DLA instrument is that many of the carers did not feel comfortable describing their child's conditions and their need for care. A number of issues may be related to this: it may be that carers were not sufficiently confident or articulate to adequately express themselves. The research process may be influential in this regard, as carers were asked to respond to a stranger. It may also be related to carers' views that it is inappropriate to discuss the extent to which they assist their children – they do not wish to be perceived as complaining about their child's health condition, and do not wish their child to be perceived as a burden. The structure of the CDAT therefore catered for carers who could not verbally express problems with their children's level of functioning as required in the DLA tool, as it provided a range of statements from which the carers could indicate the most accurate description of their child's level of functioning.

The South African instrument predominantly relies on the judgement of the Medical Officer completing the form. It consists of some open-ended questions, but mainly close-ended questions, as well as quantitative measures, particularly in the functional assessment. As the instrument is phrased, the functional assessment applies *only* to children who are four years old, and measures the child's ability to perform activities of daily living, the child's psychosocial adjustment and cognitive functioning.

The grant is legislated to provide for children from 1 to 18 years of age who satisfy the eligibility requirements. It is not clear how the functionality of children in other age groups are assessed, and one assumes that the other sections of the tool are applied to these children. Additionally, the questions asked in the assessment are inappropriate and do not adequately reflect child development or sensitivity towards children's needs and experiences. The assessment is largely dependent on the child's performance on the day of the assessment.

As indicated previously, some of the categories in the DLA tool appears to be repetitious of similar categories, indicating that such detailed categories may not be necessary in an assessment.

Categories Not Adequately Captured By The Instruments

A significant analysis of the findings is a comparison of the categories reflected in the tools (refer to chapter 2) with the additional concerns and problems that the carers had expressed. These concerns identify aspects that should be given particular attention in the South African context. This is represented below in Table 18.

Table 18: Aspects of Need Indicated by the Carers

Financial difficulties: housing, provision of basic needs, no stable income
Travelling to Hospital: costs, distance, accessibility, transport of equipment
Support structures: support from family, need for counselling
Risks to Family: employment, financial stability, property, loss of relationships
Medical Care: costs of medication, equipment & hospitalisation
Supervision/Care: costs of assistant carer
Need for Nutritious foods: costs of special foods/diet, amount of food needed

These are the additional concerns and needs indicated by the carers of the children participating in the study. These are carers who are both recipients and non-recipients of South African grants. It is essential to consider these factors, and explore further categories of need, in light of the development of an appropriate South African tool.

These aspects are not at all reflected in the CDAT, DLA tool or current South African tool. It appears to be a strong reflection of the South African context, as it reflects mainly the state of poverty and chronic lack of income that the majority of South Africans still experience. The experience of ill health and disability contributes to and exacerbates the state of poverty.

The social security system as a basic safety net plays a role in providing a number of benefits to its constituency: it should protect its members from social risks, and in the case of disability, provide and compensate for the extra costs and risks associated with disability. In the case of children, the family - primarily the carer, experiences the greatest impact of the child's condition.

Structural Aspects

It should be noted that for the majority of the interviews, the researcher was forced to repeat or rephrase many of the questions in both tools to assist the respondents' understanding of the questions. The majority of the time, language and text had to be simplified and made appropriate to the South African context.

Use of Concepts and Terminology

The DLA Tool

The most significant difference in the use of language and concepts is that the DLA tool based their questions on the caregivers' understanding of age-appropriate functioning. The condition for receiving the DLA is that the child must require more assistance or supervision *than a child of the same age who* does not have the illness or disability. The respondent is requested to identify the child's *extra needs as a result of the disability or illness*. A specific question requests carer's to indicate whether their child has suffered a delay in their development of specific skill areas. Additionally, another question refers to the use of play to stimulate the child's development.

This requires the respondent to have sufficient knowledge and understanding of child development and the corresponding needs and attention required by a child

who is healthy and developing appropriately. Also to compare a child to a peer who does not have the child's illness or disability is problematic, as children from different populations vary in their progress through developmental stages, particularly in a country such as South Africa with many diverse communities and cultures.

The expectation of carers to provide information on the premise of this knowledge base is inappropriate and unrealistic for South Africa. Most of the carers participating in this study were unable to adequately answer the given questions, hence the researcher rephrasing and asking additional questions.

Additionally, the DLA tool uses terms such as "...mental health problem", "...learning difficulty", and "...severe behavioural problems" without any definition or explanation of these terms (Disability Living Allowance: 24, Appendix C).

The DLA tool presupposes that carers are adequately educated and literate, and have a good command of language, to sufficiently provide the descriptive and comprehensive information requested.

The DLA tool does attempt to provide some form of quantitative measures, e.g., requesting how many minutes a child requires assistance with a particular activity. This kind of information is important to elicit and this is generally a useful measurement. However, the feasibility and applicability in the South African context is questionable. These questions seemed inappropriate, and did not elicit useful information when the tool was administered in this study. Carers struggled to ascertain how much time he or she spends performing a particular activity for the child or supervising the child.

Additionally, the questions are phrased in terms of the *child's need* for care or supervision, not the amount of time the carer spends performing a task. This is even more difficult, as it is requesting the carer to once again understand child development and related needs. A pertinent consideration here is that the child's needs may vary from the carer's perception of his or her responsibility to perform

a particular task on behalf of the child, thus the phrasing of these questions may not be appropriate.

The particular question requesting information about the child's mental health state is also problematic. Terms such as anxious, impulsive, frustrated and aggressive are used, which again presupposes that carer's have an average degree of literacy, as well as an awareness of their children's emotional states. There also appears to be a degree of overlap in some of the questions, e.g., there is a section that captures the child's mobility needs, and a section on the child's movement and co-ordination needs, which are very similar terms.

The CDAT

Conversely, the CDAT does not require respondents to have knowledge of child development generally, but rather to have knowledge of the concerned child's abilities and inabilities. The respondent is simply required to tick the sentence which best describes their child's ability. However, there is one option listed in every functional category: "Child's ability is the same as most other children of the same age." (Carer Allowance: 4, Appendix A). This does lend itself to the same criticism as the DLA tool – it is however, one option in a range of options.

The CDAT also uses terminology that may have different interpretations among the South African populations. There needs to be more qualification of terms and concepts. For example, within the communication category, one option provided is: "Child understands most adult conversations and concepts." (Carer Allowance: 3, Appendix A). Definitions of 'adult conversations and concepts' should be provided, as this would differ across cultures. Similarly, the term "...common objects..." is used in two options – again, this would vary across cultures and communities, and words used to describe this should be culturally sensitive (Carer Allowance: 3, Appendix A). Overall, the only sections where the use of terms is problematic are the behaviour and special care needs sections of the CDAT. Similarly to the DLA tool, the language used in the CDAT to describe the behaviour of a child is problematic, as it does presuppose a high degree of literacy and knowledge of behavioural terminology. Terms such as "...anti-social

behaviour..." and "...obsessional, repetitive behaviours..." are used (Carer Allowance: 7, Appendix A). Even more so, the special care needs section uses terminology that requires a very high level of literacy and knowledge of medical terminology, for example, "...percutaneous entero gastric tube..." and "...progressive suppurative lung disease..." (Carer Allowance: 8, Appendix A).

The South African Tool

The South African tool's use of language is fairly appropriate for the State Medical Officer who completes the forms. However, the definitions of the terms used are clearly lacking, as well as guidelines for the use of the tool. For example, definitions of what degree or types of disability constitutes "severe" disability and "...permanent home care..." are not provided (Care-Dependency Grant, 1996: 2, 3).

Utility of the Instruments

Based on the information provided above, as well as the fact that the DLA is a lengthy form (26 pages), the CDAT is far more efficient in terms of time and structure. As a result of its comprehensive and descriptive nature, the DLA took approximately 45 minutes to 1 hour to complete, while the CDAT took approximately 30 to 40 minutes. The researcher was made acutely aware of the amount of time needed for the application of the DLA when an interpreter was used, resulting in interviews of approximately 2 hours.

The structure and format of the CDAT made it simple and easy to administer. The claim form is clearly and attractively labelled, indicating what information is being requested. The Claim form for Carer Allowance (no date: 8) clearly indicates which sections carer's should complete, e.g. "Go to Part K on page 28". The structure of the functional assessment in the CDAT is easy to use, as the respondent merely ticks the appropriate box.

The structure of the DLA is cumbersome, as one has to wade through a number of questions that are not necessarily relevant to the child concerned. It uses mainly open-ended questions.

Structurally, the South African tool combines qualitative and quantitative questions. The format of the tool seems fragmented and repetitive.

ISSUES FOR CONSIDERATION RELATED TO THE SOUTH AFRICAN CONTEXT

Functional Assessment Focus versus Needs-Related Focus

Essentially, the fundamental difference between the international tools is that the CDAT is a functional assessment, while the DLA tool is focussed on the care and mobility needs of children with disabilities and illnesses. The different products of each tool are indicative of the types of questions asked. The CDAT elicits a functional score that determines a child's eligibility for the benefit; while the DLA tool elicits descriptive and qualitative information that is used by a decision-maker to determine whether the child meets the eligibility requirements of extra needs.

As these tools indicate, a needs-based tool is likely to require more descriptive and qualitative data, whereas a functional assessment tool provides information concerning the functional abilities of children related to child development stages. This is a more defined, contained measure that allows for convenient scoring and quantitative results. Conversely, the needs-based focus provides one with a holistic, detailed assessment of a child's daily living and functioning, as well as the impact of the child's functioning on his or her family. It may be feasible to combine these two methods of assessment, by developing a needs-based assessment that is easily scored and has specific outcome measures. For example, the special care needs section of the CDAT is quantified and weighted, and then combined with a functional score.

Representation of Chronic Illness versus Disability

Both the UK and the Australian tools are more biased towards disability representation than chronic illnesses. Though the Australian system does cater for some chronic illnesses, as represented in the list of recognised disabilities, the actual tool is not sufficiently sensitive to the needs and functioning of children with chronic illnesses. The DLA tool, for example, identifies its eligibility criteria as

mobility and supervision needs - two factors that are not necessarily relevant to children in the early stages of chronic illnesses. As is evident from the responses to the DLA instrument, only 1 child with a chronic illness required supervision, related to the illness, both day and night. Similarly with regards to mobility, only 2 children with a chronic illness were identified as having mobility problems.

This trend is persistent throughout the DLA tool. In activities for daily living, significantly children with HIV/AIDS appear to require no or little assistance to accomplish these activities. At the time of the interviews, these children were still in relatively good health, hence their age-appropriate functioning and ability. It is also significant that across all the chronic illnesses in the sample, reference is made to periods of poor health, indicating the fluctuating nature of the illnesses, which results in periods of good health and periods of poor health. This indicates that the children's functional abilities also fluctuate.

Though the DLA tool allows one to capture information about the fluctuating nature of a condition because of it's open-ended questions, it does request that the respondent indicates the child's behaviour and needs that are constant (Disability Living Allowance, Appendix C). In addition, the phrasing of the questions does not indicate an allowance for health conditions that fluctuate. This discrepancy is notable with 2 of the children with cancer – though both children were healthy at the time of the interview, carers reported that during their periods of poor health, both children had regressed from being toilet-trained to both soiling and wetting the bed constantly. The DLA tool did not adequately capture these children's fluctuating health conditions.

Similarly, the CDAT is even less accommodating of children with fluctuating health conditions. A specific instruction in the functional assessment indicates that a child should be able to perform the activity "...consistently or on a daily basis" (Carer Allowance: 2, Appendix A). With most of the children with chronic illnesses, carers were ambivalent when responding to the CDAT, being aware that their children could generally accomplish a certain task, but would not be able to accomplish that task during periods of ill health. Carers of children who had cancer noted that when their children were ill, the only response that would be appropriate to the

domains of dressing, social and community and hand movement, for example, is "Child cannot do any of the things listed above" (Carer Allowance: 3, Appendix A). This occurred because the child's health and functioning had deteriorated from being age-appropriate to lower levels of functioning during the periods of illness.

Inclusion of Social And Environmental Factors

Both the DLA instrument and the CDAT did not specifically measure social and environmental factors, though they indirectly captured some information pertaining to these factors.

The DLA instrument includes questions pertaining to the child's environment and social context. For example, it requests information about the child's indoor mobility needs – specifically requesting whether the child's home requires adaptation to enable his or her ease of mobility indoors. Similarly, the question requesting information about the child's needs when he or she goes out during the day does indicate the child's needs when involved in social and religious activities. This has been identified in other tools as a category of assessment, such as the Life-H questionnaire (Fougeyrollas, et al, 1988: 131). However, these identified environmental and social factors are limited.

What is most advantageous of the DLA is that the open-ended questioning allows the respondent to relate the difficulties and problems arising for the child as a result of his or her context. For example, one carer was able to share her struggle to transport her child with a physical disability to hospital because transportation of the child's buggy using public services posed difficulties. The other questions in the tool did not capture this information. Thus, the method of assessment allows for the identification of environmental and social factors that may be hindering or promoting the child's ability to function. However, though these factors are highlighted through the assessment process, the DLA instrument does not specifically refer to social and environmental factors, other than those indicated above.

Similarly, the CDAT has one section that considers environmental factors, i.e., social and community skills. However, the method of assessment is focussed on the child's functional abilities, therefore the instrument elicits information on the child's ability to function within social and community contexts, and not on the impact of these settings on the child's functioning. There is a minimal amount of options for the caregiver related to actual environmental and social factors.

Thus, these two instruments lack the meaningful inclusion of the impact of social and environmental factors on the child's ability to function. This does limit it's usefulness for the South African context, as the contextual limitations, for example, lack of adequate transport facilities, does impact greatly on the children's ability to function optimally in their environments.

Measures of Assessment

The DLA's primary concepts used as measures of assessment are the extra care and attention a child requires due to his or her health condition, and the times and frequency that the child's extra needs occur. The United Kingdom's system attributes a significant distinction on whether a child's needs occur during the night or during the day. This aspect determines whether a child will receive the higher or middle rate of care. This seems an arbitrary concept whereupon the rate of care is determined. It appears to undermine the significance and intensity of the child's extra needs by qualifying and distinguishing a child's need for care, and the amount of benefit received, by day or night time care. Once again, the United Kingdom's concepts and measures seem to be artificial and removed from the reality of the disability experience.

Though the CDAT focuses purely on the functional abilities of children and does not consider their attention or supervision needs, it is assumed that a child with marked functional deficiencies would require substantial care and attention. The children who obtain a qualifying score on the CDAT would have significant care needs and would thus receive the benefit.

However, the health professionals' report for the CDAT requests the amount of hours that a child requires care and attention as a result of his or her disability. If the child's care and attention needs exceed 14 hours per week, he is eligible for the Health Care Card. Similar to the DLA tool, for carers or health professionals to determine the extent of care and attention required with reference to time seems inappropriate for the South African context. The burden of care for South African caregivers is a much more complex phenomenon than a mere reference to time.

INTERPRETATIONS OF THE FINDINGS

Perspectives and Definitions of Disability

According to the World Health Organization's (1993) framework for disability, there are three levels of the disability experience: the organic, disability and handicap level. Considering these levels of disability it is evident that the CDAT primarily operates at the disability or functional level, as it assesses the child's ability to function. In contrast, the DLA tool predominantly functions at the disability and handicap level, as it captures the needs of children in relation to their impairment. The South African tool mostly functions at the organic and disability level, the focus of the tool being the medical perspective.

None of the tools embraces the social model completely, which addresses the social and economic conditions that may result from impairment. Of the three instruments, the DLA tool incorporates the social model to a greater extent than the other two tools. Thus, the medical model is the underlying premise, to varying degrees, in all three tools, especially as the three tools compare a child with impairment to 'normal' children of same age.

However, as attempted by the ICF, a holistic model would incorporate all of these perspectives – the organic, disability & social realms of impairment. Haley, et al (1994) proposes the inclusion of contextual & social factors in relation to assessing functional ability – function must be described within a contextual framework. As can be seen by the literature reviewed, the assessment of contextual factors would include the child's socio-economic conditions & living environments, as well as

family relationships. The assessment of these factors would include financial burden, costs of caring, and need for services. None of the tools evaluated in this study sufficiently incorporates these factors in their assessment processes.

Assessment Processes

It is important to note that the purpose of a programme influences the definition and approach to disability that is assumed (Aron, et al 1996).

Noticeably, the United Kingdom's assessment process is similar to the 'consequence of disease' approach that is described by Stein, et al (1993). The United Kingdom's approach describes the impact if the child's condition, which is then used to determine the rate of care or mobility awarded to the child. In light of Stein's approach, the severity of the condition is determined by evaluating the impact of the condition on the child's daily functioning, using predetermined consequences, i.e. mobility & care needs. The child is awarded a rate of care or mobility determined by the level of severity (lower, middle and higher).

Thus the DLA tool assesses the social implications of living with the health condition, which is also a characteristic of the non-categorical approach. It uses predominantly qualitative information to capture the consequences of the condition, rather than quantitative. It does not simply rely on medical diagnoses, but employs the caregivers' perspective, who is presumed more aware of the child's needs and environmental context than the health professional.

The CDAT merely measures the child's functional ability for the purposes of grant eligibility, not considering the extra care needs of the children. This is sufficient to elicit the information required to determine eligibility, as the Australian system is based on the definition that a child with a disability has sufficient functional impairment to require care. It is thus significant that the children who were found eligible were those with care needs as evident when considering the rate of care they were awarded under the United Kingdom's system.

In comparison to the other tools, as well as those examined in the literature review, the South African tool does not adequately measure the functional limitations of children. It does not include social factors or environmental factors at all, and does not measure the resultant needs of children with chronic health conditions.

Categories of Assessment

Aron et al (1996) describes the 'burden of illness' and the 'burden of care' concepts in relation to measuring the needs of children with disabilities. The burden of illness concept concerns the child's needs related to the health condition. This concept is similar to the Lifestyle Assessment Questionnaire (LAQ), described previously, which contains the category 'clinical burden'. The burden of care concept combines the needs related to services & resources. It is evident that the United Kingdom's tool captures both concepts in the broad category of care needs. The CDAT captures these categories, however, to a limited extent, in the special care needs and behaviour domains.

Consistent with the tools described in chapter 2, such as the LAQ, the PEDI and the LIFE-H questionnaire, the three tools elicit information about the child's ability to accomplish activities of daily living. The LAQ, the LIFE-H questionnaire and the PEDI contain categories describing the child's extent of assistance required to accomplish these tasks. The United Kingdom's tool extensively captures this information. However, the South African tool and the CDAT do not directly refer to the child's need for assistance in these areas.

The LAQ contains a category reflecting the impact of the impairment on the child's education, as well as describing the economic burden on the family as a result of the child's health condition. Additionally, it provides a category describing the impact of the condition on the child and family's social integration. None of the tools have categories of assessment related to the child's education, though the DLA tool requests minimal information concerning the child's schooling. None of the tools address the economic burden on a caregiver or family - the South African system applies a means-test to the applicants of the grant, but this does not

measure the costs incurred as a result of the child's condition. Similarly, categories reflecting the social and environmental impact are minimally applied in the DLA tool and the CDAT, and not at all applied in the South African tool.

THE DATA: CONFIRMATIONS AND DEVIATIONS

As the findings indicated, the Australian system included the vast majority of the children as eligible for its benefit. This was a very similar pattern to that of the United Kingdom's performance. This was a surprising result, as these two social assistance programmes, and assessment processes for children with disabilities, are very different. The reason for this performance by the Australian system is related to its definition of a child with a disability as having sufficient functional impairment to require care. It is also surprising that the United Kingdom's tool, though more needs based than the Australian tool, is fairly inappropriate for the South African context in relation to utility and efficiency.

The findings indicate that the vast majority of the children in the sample have significant needs related to their health conditions. The results also confirm that the South African system minimally provides for children with chronic illnesses, children with temporary health conditions and children with mild or moderate disability, which was expected. As the sample only included children attending a tertiary health care facility, it minimally included children with mild or moderate needs related to their health conditions.

SIGNIFICANCE OF THE FINDINGS

The findings are significant as they primarily reflect the continual battle that the majority of South Africans experience who are caring for a person with a disability, or who are experiencing some form of disability. The harsh reality is that the social and environmental barriers that hinders persons, particularly children, with disabilities fundamentally exists because of poverty. These results confirm that poverty plays a significant role in the lives of children with disabilities and their caregivers.

Related to the impact of poverty and the impact of their health conditions, these children experience a vast array of needs, including health care needs, transport needs, and the need for support. The results provide evidence that the current South African social assistance programme is not providing for the majority of these children, and not catering for the majority of their needs, such as transport needs. The exclusion of certain health conditions from eligibility, and the inappropriate assessment tool, suggests discriminatory practices within the current South African system – practices that do not incorporate a rights-based approach or prioritise the needs of vulnerable children.

This study also evaluates existing assessment instruments and processes that attempt to capture the social assistance needs of children with chronic health conditions. Thus, categories of need and measurements used in other contexts have been identified and may prove useful for the South African context.

CONCLUSION

This chapter presents and discusses an analysis of each tool and considers key factors in relation to the South African context. It also presents an interpretation of the findings, discusses confirmations and deviations of the data and considers the significance of the findings. The following chapter provides the conclusions of this study and makes recommendations for a more comprehensive South African social assistance programme for children with chronic health conditions.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

This chapter will discuss the main findings in relation to the overall objectives of the study. The relevance of this study will also be described in relation to policy implications and where appropriate, recommendations for policy development will be made.

THE CHILDREN AND CAREGIVERS' NEEDS AND EXPERIENCES

In summary, the findings clearly indicate that the children participating in this study had substantial needs related to their health conditions, in particular children with chronic illnesses.

A number of exacerbating factors influenced the caregiver's ability to provide adequate care for these children. Additionally, the caregiver's and their families experienced a number of consequences and costs that resulted from providing care for a child with a chronic health condition. These factors were particularly pertinent for the carers of children with chronic illnesses. They greatly impacted on the quality of care provided to the child concerned and the emotional and psychological well being of the carers.

The findings indicate that the carers' socio-economic status exacerbated the effects and consequences of providing care for children with chronic health conditions. The majority of these families required financial and other forms of assistance to help the caregivers cope with the burden of providing care.

THE APPLICATION OF TWO SOCIAL ASSISTANCE SYSTEMS

The United Kingdom's and the Australian social assistance assessment instruments for children with chronic health conditions were applied to the sample of children. The results indicated that a high percentage of these children were eligible for the social assistance benefits of both the United Kingdom's and Australian systems. Both systems found a high percentage of children with chronic

illnesses eligible for their benefits. In contrast, the South African social assistance assessment instrument, when applied, indicated that only a small percentage of these children were eligible for the South African benefit. A large percentage of the children excluded by the South African system are those with chronic illnesses.

Given these differences in eligibility status between the three systems, the assessment tools and processes were analysed. The following section summarises the outcomes of the analysis.

Pertinent Aspects of the Two International Systems and Instruments

Both international systems and tools contained aspects that appropriately captured and measured the needs of the children in the sample. These aspects are discussed below.

The United Kingdom's DLA tool allows descriptive, holistic and needs-related information pertaining to the child to be captured via an open-ended questionnaire. The decision-maker makes an assessment using this information to determine the child's eligibility for the benefit. In particular, the child's need for caregiver assistance is given substantial consideration. The children are awarded differential rates dependent on their needs, allowing children with lesser needs to receive social assistance as well. Thus, the severity of needs due to the health condition and its impact on the child and caregiver are the primary aspects whereupon assessment for eligibility for the benefit is based. This needs-based approach appropriately captured the situation of the children and carers in the sample, including children with chronic illnesses.

Though the CDAT incorporates a functional approach to assessment, it also includes the assessment of special care needs and behaviour. These two categories hold greater value in the assessment process than other categories. The Australian system uses the list of health conditions and the assessment instrument, ensuring that social assistance assessment is available for children with a range of conditions and levels of severity. The CDAT appears to be a

reliable, quantifiable measure of assessment that captured children in the sample with significant needs, including children with chronic illnesses.

Considering the performance of the two international instruments and their relevant aspects, the current South African instrument failed to adequately capture the social assistance needs of the children in the sample; neither does it contain reliable or appropriate measures or indicators for assessment. The international systems and tools reveal the deficiencies in the current South African system and tool. There is therefore a need to reconsider the current South African social assistance provisioning and assessment of children with health conditions in light of the context of children with chronic health conditions in South Africa. In particular, serious attention must be given to the socio-economic conditions of families in South Africa and its interaction with the provision of care for children with health conditions. This study particularly highlights the need to develop a more appropriate instrument for the social assistance assessment of children with health conditions.

POLICY IMPLICATIONS

The following section provides recommendations in relation to South Africa's social assistance provisioning and assessment of children with health conditions. In light of the scope of this study and its limitations, this study is able to inform broad policy agendas with reference to policy formulation and implementation. Based on the findings of this study, key aspects of policy pertaining to children with chronic health conditions are highlighted. It is suggested that policies are revisited at a conceptual level as well as a practical level.

As the current Care Dependency Grant assessment tool is outdated, and was implemented during a period when few options other than permanent home care was available to caregivers, the following policy implications are considered.

Policy Formulation

The Scope of the Care Dependency Grant

It is suggested that the overall scope and purpose of the Care Dependency Grant is reconsidered in light of the current South African context and the services and opportunities available to children with disabilities and their families. It is recommended that policy-makers give serious consideration to the extension of social assistance to children with health conditions other than severe, permanent, intellectual and physical disability. Vulnerable groups of children such as those suffering from poverty-related illnesses, e.g., malnutrition, and in particular those with chronic illnesses should be considered as high priority groups. Thus, an essential consideration for policy-makers is the broadening of the definition of social assistance provisioning for children with health conditions.

In relation to this, definitions of children with health conditions that would be targeted for eligibility should be provided. Definitions would be dependant on the approach that policy-makers assume, i.e., a social model of disability would define these children according to their resultant needs and contexts, while a medical model would emphasise the health conditions at an organic or functional level (Refer to chapter 2 for a discussion of definitions of disability).

A Holistic Approach to Eligibility Assessment

Based on the purpose of the grant and its target population, it is suggested that policy-makers revise the current criteria for determining eligibility, which is situated within the framework of the medical model. It is recommended that a holistic approach to the circumstances of children with chronic health conditions and their caregivers be taken into account in the assessment process. A holistic approach would incorporate a needs-based assessment rather than a means-test and would include an assessment of the caregiver's socio-economic status. Additionally, it would include an assessment of the child's need for caregiver assistance, assistive devices, or other means of assistance. A holistic approach would consider the impact of the health condition on the child, caregiver and family, including the costs and associated risks of providing care for the caregiver.

Another important consideration would be the impact of family characteristics, social, and environmental factors on the child's overall functioning.

The function of the medical diagnosis in determining eligibility should be carefully considered. It is proposed that the medical diagnosis is not given greater emphasis than the *needs resulting from the health condition* - this should be the fundamental precept for determining eligibility. This would represent a shift away from the present medical model towards a social model, which would be more consistent with contemporary approaches to social assistance and programmes for children with health conditions.

Policy Implementation

Eligibility Determination

Regarding the procedure of eligibility determination for social assistance, it is recommended that a simple, user-friendly process be developed. Policy-makers should consider the end-users of the assessment process, i.e., disability panel members at a local level. A basic mechanism of scoring or rating could be applied to the assessment. A process that applies greater weighting to particular categories of need may be useful to ensure that children with particular needs are prioritised, e.g., health care categories.

Fiscal Considerations

In light of economic limitations on social assistance provisioning, it is suggested that a phased-in approach be adopted, i.e., levels of need due to the health conditions are identified, and children with high rates of need are initially prioritised for benefits. In addition, policy-makers should consider the feasibility of providing indirect social assistance such as subsidised transport services or medical services for children with chronic health conditions. These services could also be provided to children with particular rates of need, e.g., children with lower levels of need are eligible for subsidised transport services.

Issues For Further Research

This study was able to capture limited information regarding the needs of a small sample of children with chronic health conditions from predominantly low socio-economic communities in the South African context. It is necessary to collect large-scale information pertaining to the needs, experiences and circumstances of children living with chronic health conditions in South Africa - in particular, the impact of social and environmental factors. This would supplement the findings of this study and substantially inform policy processes regarding social assistance for children with chronic health conditions.

The resultant burden experienced by caregivers of children with chronic health conditions should also be explored further – issues relating to employment, financial costs, time and other resources. Issues pertaining to the caregiver's support systems and coping strategies should also be explored.

CONCLUSION

The final chapter presented a discussion of the salient aspects of this study. In light of these aspects, policy implications are discussed in relation to social assistance policy for children with health conditions in South Africa. Particular attention is paid to the development of an appropriate assessment instrument. Finally, issues pertaining to children with chronic health conditions in the South African context that require further research are indicated.

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APPENDIX A: THE AUSTRALIAN CHILD DISABILITY ASSESSMENT TOOL (CDAT)

AND NOTES ON ITS DEVELOPMENT

Customer Reference Number

Date / /

To return this form,
fold the form and place it in the reply paid envelope so that this address appears in the envelope window.

Centrelink
Linking Australian Government services

Carer Allowance

Functional assessment for a child–under 16 years

Centrelink requires information from you to add to the information provided by your doctor. This will be used to:

- assess your eligibility for fortnightly payment of Carer Allowance; or
- review your details to see if you can continue to be paid Carer Allowance.

Please answer the questions in this form and return it to your local Centrelink Customer Service Centre as soon as possible. If you do not get this information to us within 14 days of receiving this form, your Carer Allowance might be rejected or cancelled. If you have trouble getting this information, please contact Centrelink immediately.

This is an information notice given under the social security law.

This form must be filled in by the parent/guardian

Child's details

Child's family name

Given name(s)

Date of birth

FOR MORE INFORMATION

13 2717

If you need help to answer any of these questions please call 13 2717 during normal business hours for the cost of a local call, or contact your local Centrelink Customer Service Centre.

Notes about | Functional assessment

Functional assessment

- The functional assessment is used to determine entitlement to the fortnightly payment of Carer Allowance.
- The functional assessment asks general questions about the child's ability to function in key areas.
- Its purpose is to measure the impact of a disability/medical condition on the child and family in terms of the child's functional abilities. It **does not** measure the care and attention required by the child.
- It **does not** ask questions about specific disabilities/medical conditions. This is because it is designed to identify the level of disability regardless of the type of disability/medical condition.
- The functional assessment examines the ability of the child to function at the level appropriate to his/her age.

Instructions for Questions 1–8

- This assessment requires the completion of two parts of this form:
  - Functional assessment (Questions 1–8);
  - Behaviour and special care needs (Questions 9–10). Not covered by SA form
- Questions 1-8 are based on eight functional areas for a child.
- For each question, the tasks/abilities are listed from the most difficult at the top of the list to the easiest at the bottom of the list.
- Please tick the statement listed in each question that describes your child's BEST ability in the area (that is, read each list and tick the most difficult task your child can perform):
  - the child has the ability to do the functions listed when using aids, appliances or special equipment items;
  - he/she can do the task when given the opportunity;
  - he/she can do the task consistently or on a daily basis;
    e.g. the child cannot be said to "manage his/her own toileting with minimal assistance" unless he/she can do so more or less every day.
  - he/she can do the task to a reasonable standard;
    e.g. the child has the ability to "crawl or otherwise propel him/herself along" only if he/she can do so without difficulty.
  - where the task is in two parts, the child must be able to do **both** parts;
    e.g. *"child can read and interpret a paragraph from the front page of a daily newspaper"*;
  - if your child cannot do any of the things listed, tick the second last box;
  - if your child's ability is the same as most other children of the same age, tick the last box.

PART A | Functional assessment

Listening, reading and understanding

1 Communication– Listening, reading and understanding:
Tick the box which describes your child's best ability.
Tick one box only.

D3
3.1

- ☐ Child understands most adult conversations and concepts. C-1j
- ☐ Child can read and basically understand a newspaper. C-1i
- ☐ Child can read and understand a short story written for children of the child's age group. C-1h
- ☐ Child understands basic adult speech and can read and understand simple written words. C-1g
- ☐ Child follows complex instructions with two or more steps (e.g. 'pick up the book and put it on the chair'). C-1f
- ☐ Child can show or say what common objects are used for. C-1e
- ☐ Child recognises pictures of common objects and animals. C-1d
- ☐ Child responds to his or her own name. C-1c
- ☐ Child listens and turns his or her head towards sounds. C-1b
- ☐ Child looks briefly at your face when you talk to the child. C-1a
- ☐ Child cannot do any of the things listed above. C-1x
- ☐ Child's ability is the same as most other children of the same age. C-1i

Talking, writing or signing

2 Communication–Talking, writing or signing:
Tick the box which describes your child's best ability.
Tick one box only.

D3
3.2, 3.3

- ☐ Child can discuss and debate complex issues such as politics or religion with an adult. C-2j
- ☐ Child can describe the child's experiences in detail using complex sentences. C-2i
- ☐ Child can tell a complex story involving several people and child can write a short story. C-2h
- ☐ Child can write the child's own first name by handwriting or typing. C-2g
- ☐ Child talks or signs well and can use six or more words in a sentence. C-2f
- ☐ Child can say or sign sentences with three to four words. C-2e
- ☐ Child can clearly say or sign more than 20 words and use two words in combination (e.g. 'Daddy's car'). C-2d
- ☐ Child can say or sign three or more simple words (e.g. 'mum', 'dad', 'drink', 'bed'). C-2c
- ☐ Child smiles and babbles or makes purposeful sounds (e.g. to attract attention). C-2b
- ☐ Child can make a sound other than crying. C-2a
- ☐ Child cannot do any of the things listed above. C-2x
- ☐ Child's ability is the same as most other children of the same age. C-2i

PART A | Functional assessment

Feeding and mealtime skills

3 Feeding and mealtime skills:
Tick the box which describes your child's best ability.
Tick one box only.

- ☐ Child can use all cooking equipment and kitchen appliances (e.g. microwave oven, electric frypan, or mixer) without assistance. C-3
- ☐ Child can follow a recipe and prepare a simple meal. C-3i
- ☐ Child can cook a simple snack (e.g. toast). C-3h
- ☐ Child can prepare a simple uncooked snack (e.g. a sandwich). C-3g
- ☐ Child can use a fork and spoon at mealtimes. C-3f
- ☐ Child can eat most solid foods if food is cut up (e.g. raw apple). C-3e
- ☐ Child uses spoon well. C-3c
- ☐ Child can drink from a normal cup without help and can feed himself or herself with finger foods. C-3d
- ☐ Child can drink from a modified cup when the cup is held by you. C-3a
- ☐ Child can suck from a breast or baby's feeding bottle. C-3a
- ☐ Child cannot do any of the things listed above. C-3k
- ☐ Child's ability is the same as most other children of the same age. C-3l

Hygiene and grooming skills

4 Hygiene and grooming skills:
Tick the box which describes your child's best ability.
Tick one box only.

- ☐ Child can style own hair and clean and cut own finger and toe nails without assistance. C-4i
- ☐ Child can attend to basic hygiene (e.g. toileting, showering and brushing hair) without assistance. C-4h
- ☐ Child manages basic hygiene (e.g. toileting, showering and brushing hair) with little assistance. C-4g
- ☐ Child can wash hands and face and brush own teeth. C-4f
- ☐ Child is reliably toilet-trained during the day and can manage own toileting with minimal assistance. C-4e
- ☐ Child can indicate toilet needs during the day but needs some assistance with clothing and wiping. C-4d
- ☐ Child remains dry during the day when toileted regularly after meals and drinks. C-4c
- ☐ Child requires full assistance with toileting. C-4b
- ☐ Child cries when nappy is soiled or wet. C-4a
- ☐ Child cannot do any of the things listed above. C-4j
- ☐ Child's ability is the same as most other children of the same age. C-4k

PART A | Functional assessment

Dressing skills

5 Dressing skills:
Tick the box which describes your child's best ability.
Tick one box only.

D 2
2.4

- Child can purchase and care for own clothing without assistance. C-5j
- Child can wash and iron own clothing if required to with little assistance. C-5i
- Child can choose own clothing appropriate to the weather and can dress and undress without assistance. C-5h
- Child can do up buckles and untie shoelaces. C-5g
- Child can do up buttons and zippers. C-5f
- Child dresses and undresses self but needs assistance with buttons, laces or tight clothing. C-5e
- Child can undress with little assistance. C-5d
- Child tries to help with dressing. C-5c
- Child lifts arms to be picked up. C-5b
- Child snuggles into an adult when cuddled. C-5a
- Child cannot do any of the things listed above. C-5k
- Child's ability is the same as most other children of the same age. C-5l

Social and community skills

6 Social and community skills:
Tick the box which describes your child's best ability.
Tick one box only.

D 4
4.1

- Child can use all major community facilities (e.g. shops, banks, doctors) with little assistance. C-6j
- Child is able to undertake basic activities in the community (e.g. shopping) with little supervision. C-6i
- Child understands basic personal safety (e.g. how to cross the road and not to go with strangers). C-6h
- Child is aware of being left in the care of others (e.g. school teacher or child care worker) without getting unduly upset. C-6g
- Child plays with other children and forms close friendships with other children. C-6f
- Child knows whether he or she is a boy or a girl. C-6e
- Child initiates contact with other people and involves other people in games or activities. C-6d
- Child responds to affection from familiar people. C-6c
- Child laughs and giggles when happy and cries when upset or angry. C-6b
- Child smiles. C-6a
- Child cannot do any of the things listed above. C-6k
- Child's ability is the same as most other children of the same age. C-6l

PART A | Functional assessment

Hand movement

7 Hand movement:
Tick the box which describes your child's best ability.
Tick one box only.

D5
5.1

- Child can use a variety of tools or hobby items with accuracy (e.g. for woodwork, sewing, painting or model building). C-7j
- Child can write clearly. C-7i
- Child can write all letters of the alphabet clearly. C-7h
- Child can hold a pencil and draw basic shapes such as squares and triangles. C-7g
- Child can draw at least a head and body of a person stick figure style. C-7f
- Child can copy a circle and a cross. C-7e
- Child can use larger objects and toys (e.g. the child can push or pull toys, use posting box toys, build small tower of blocks). C-7d
- Child can make purposeful movements with objects (e.g. bang on a drum or clap hands). C-7c
- Child can hold and let go of objects such as a rattle or feeding bottle. C-7b
- Child can hold an adult finger but may need help to release it. C-7a
- Child cannot do any of the things listed above. C-7k
- Child's ability is the same as most other children of the same age. C-7l

Body movement

8 Body movement:
Tick the box which describes your child's best ability.
Tick one box only.

D1
1.1 – 1.5

- Child can hit a ball with a bat and can kick a ball with reasonable accuracy. C-8i
- Child skips well and can catch a small ball (e.g. a tennis ball). C-8h
- Child can jump and can hop on each leg. C-8g
- Child can hop on one leg. C-8f
- Child can pedal a tricycle. C-8e
- Child can walk and can run a few steps. C-8d
- Child can pull himself or herself from floor to a standing position and may be able to stand independently. C-8c
- Child can crawl or move himself or herself along the floor. C-8b
- Child can raise head off floor when lying on his or her stomach. C-8a
- Child cannot do any of the things listed above. C-8j
- Child's ability is the same as most other children of the same age. C-8k

PART A | Functional assessment

Instructions for Questions 9–10

- Please indicate **all** statements that describe your child's behaviours or special care needs.
- The questions should be left blank if none of the statements apply to the child.
- Your response should be based on the child's behaviour when they are receiving any prescribed medication.

Behaviour

9 **Behaviour:**

Read the list and tick **all** statements that apply to your child.

No equivalent on SA form

The child is only taken into community settings when unavoidable because of the child's extreme anti-social behaviour.	☐ C-9a
Child purposefully injures himself or herself through head banging, hand biting or other forms of self abuse.	☐ C-9b
Child displays explosive and unpredictable violent behaviour towards other people or property at least once a month.	☐ C-9c
Child is aged five years or older and has poor awareness of danger (e.g. runs into traffic or jumps into water without being able to swim).	☐ C-9d
Child continually runs away. Child requires constant supervision and house and other care settings must be locked.	☐ C-9e
Child is extremely active and is unable to concentrate on a task for more than 30 seconds.	☐ C-9f
Child's behaviour is such that the child cannot be left with anyone other than the parents or outside the parent's home.	☐ C-9g
Child displays obsessional, repetitive behaviours (e.g. obsession with particular objects or twirling or spinning objects for extended periods of time).	☐ C-9h
Child is obsessed with following specific routines and becomes extremely upset and disturbed if regular routine is disrupted.	☐ C-9i

PART A | Functional assessment

Special care needs

10 Special care needs:
Read the list and tick **all** statements that apply to your child.

- Child receives all food and fluids by nasogastric, gastrostomy tube or percutaneous entero gastric tube (PEG). ☐ C-10a
- Child has a tracheostomy. ☐ C-10b
- Child is aged over four years and is incontinent (i.e. wets or soils his or her pants or nappies) both day and night. ☐ C-10c
- Child is aged over three years and cannot stand without support. ☐ C-10d
- Child requires a wheelchair and needs assistance to propel the wheelchair. ☐ C-10e
- Child requires a wheelchair, quad sticks, prosthesis, crutches or walking frame but can move around with little assistance using this equipment. ☐ C-10f
- Child uses an electric wheelchair. ☐ C-10g
- Child requires urinary catheterisation several times each day. ☐ C-10h
- Child requires specialised equipment, prosthesis, or technology to communicate (e.g. a computerised communicator, telephone typewriter (TTY), voice synthesiser, cochlear implant, hearing aids or adaptations to a standard computer). ☐ C-10i
- Child is aged over five years and requires care provided by parents more than twice each night between the hours of 10pm and 6am. ☐ C-10j
- Child is aged over five years and has persistent difficulties with memory, concentration, planning and organisation. ☐ C-10k
- Child has chronic and progressive suppurative lung disease for which ongoing daily airway clearance is provided and/or enzyme replacement therapy and nutritional supplements are required and provided on a daily basis. ☐ C-10l
- Child has an inherited metabolic disorder that is being treated by medically prescribed diet as the basis of treatment so that it will not lead to neurological disability. ☐ C-10m
- Child is assisted with the administration of medication on a daily basis to control seizures and medication does not substantially reduce the frequency of seizures and the child may require immediate or emergency attention to prevent harm resulting from a seizure. ☐ C-10n
- Child is assisted on a daily basis with at least two blood tests to measure blood glucose levels, injections and special dietary management and the child is not capable of determining medication levels, food intake or self administration of medication. ☐ C-10o

PART B | Statement

11 Your statement:

I declare that

- the information I have given is true and correct.

I understand that

- deliberately giving false or misleading information is a serious offence.
- personal information is protected by law and can be given to someone else only in very special circumstances, where Commonwealth legislation requires or where I give permission.

Signature

Date / /

12 Returning this form:

Please return this form to your local Centrelink Customer Service Centre in the envelope provided.

Development of the Child Disability Assessment Tool – Timeline

(as at 21.3.2002)

The Child Disability Assessment Tool (CDAT) is utilised to assess a child's level of functional ability against what might normally be expected of a child at their age (developmental milestones). The tool includes a list of manifest conditions that confer automatic qualification for Carer Allowance (formerly Child Disability Allowance).

If two children in a family are each below the qualifying threshold in the assessment tool, but together have a score exceeding the threshold, one Carer Allowance may be paid.

Children who do not meet the qualifying threshold in the assessment tool, or do not qualify under the manifest conditions list, may be granted a Health Care Card. Their additional care and attention needs must be above that expected for a child of their age without a disability, and exceed 14 hours per week.

1993 Work on the development of the Child Disability Assessment Tool (CDAT) commenced in 1993 as part of a review of the Child Disability Allowance (CDA) program. In October 1993, a policy discussion paper produced by the Department of Social Security identified a number of directions for reform. 1200 copies of the paper were circulated to community organisations. Written responses were overwhelmingly supportive of the proposal to develop an assessment tool that measured disability.

1994 – 1995 Coopers and Lybrand were engaged to test the feasibility of developing child disability tables that assess the child's level of functional ability. Functional assessment tables and scoresheets were developed in consultation with a medical reference group. Over 500 claimants completed and returned a survey focused on the adapted scoresheets. Based on a comparison of the data resulting from claimant, treating health professional, Department of Social Security and Australian Government Health Service assessments of the functional ability of a given child, the study concluded that child disability tables were a feasible way of testing eligibility for CDA. This conclusion was established by considering the performance of the data against four criteria: validity; reliability; bias; and administration.

1996 The draft assessment tool and the parent and treating health professional questionnaires were developed by the department with assistance and advice from Ernst and Young (Adelaide). The consulting team included staff with qualifications in paediatric medicine, nursing and intellectual disability, psychology and speech pathology. Additionally, the draft assessment tool was developed with the aid of three reference groups that included experts from advocacy groups and health professionals dealing with children and was overseen by a Steering Committee in which representation included peak disability organisations and specialists in childhood disability.

1996 – 1997 The draft questionnaires were distributed in two field tests during late 1996 and early 1997. Over 800 claimant and over 400 treating health professional questionnaires were returned for assessment. In addition to this claimants and treating health professionals were asked to provide comments on the questionnaires. These comments, along with the assessment of the questionnaires, assisted with the refinement of the questionnaires.

1997

In June 1997, a consultation paper was released to over 350 organisations inviting comment on the draft assessment tool. There were over 80 written submissions, many assisting with the refinement of the tool.

On 10 November 1997 the Senate Community Affairs and Legislation Committee held a public hearing on the assessment tool. The Department presented a submission and other organisations gave evidence.

1997 - 1998

The legislation relating to the implementation of the new tool was passed and the Government announced in the 1997 - 1998 budget that, from 1 July 1998, new claimants for CDA would be assessed under the CDAT.

1998

On 1 July 1998 two levels of CDA were introduced. One provides for a fortnightly payment and a Health Care Card and qualification is determined by using the CDAT or by using lists of severe disabilities and chronic medical conditions that permit automatic entry to the program. The second level of assistance provides for a Health Care Card for children with disabilities who require at least 14 hours per week of additional care and attention. The CDAT is not used to assess this level of assistance.

1999

On 1 July 1999 CDA was combined with Domiciliary Nursing Care Benefit (administered through the Commonwealth Department of Health and Aged Care). The combined payment is known as Carer Allowance (CA) and is administered by the Department of Family and Community Services.

2000

An evaluation of the CDAT and new assessment arrangements was completed in March 2000. The evaluation methodology included the collection and analysis of data from three sources: a full Centrelink data set on CA customers; feedback from four focus groups of Centrelink staff nationwide; and written submissions from community, peak organisations and medical professionals with an interest in child disability issues, individuals and parents. A reference group comprising medical experts and representatives of peak organisations advised the department on the evaluation by considering and commenting on issues raised in submissions.

June 6 2000 –the evaluation report on the CDAT was tabled in Parliament by Senator Herron, in Senator Newman's absence.

June 7 2000 – the Government response to the evaluation report on the CDAT was tabled in Parliament.

2000 – 2001

The implementation of the recommendations of the evaluation accepted by Government were completed.

2002

The revised *Child Disability Assessment Determination 2001* (CDAD) is effective 1.1.2002.

A review of the Recognised Disabilities Lists contained in the CDAD will commence during 2002.

APPENDIX B: THE AUSTRALIAN CDAT

A SUMMARY OF THE CLAIM FORM, THE FUNCTIONAL ASSESSMENT AND THE SCORING PROCESS

THE CLAIM FORM

The claim form consists of three sections relevant to the carer applying for Carer Allowance.

Section A comprises questions concerning the carer's background information and personal details. For example, questions that address residency status, contact details, marital status and employment status are included. Questions on payment details are also included, as benefit payments are made into the bank and similar provisions.

Section B requests information about the child being cared for. Information such as the number of children with disabilities that is in the applicant's care, and personal details about the child, including the relationship of the child to the carer, if any, is requested. Other information that proves relevant is details about the child's main health condition, details about the length of time the child has been in the applicant's care, whether the applicant is receiving any other benefits for the child and details about regular periods when the child is not in the applicant's care.

Section C consists of claim details, and the final section requires the applicant to sign a statement of consent. A checklist and information about necessary accompanying documentation is provided at the end of the form.

THE FUNCTIONAL ASSESSMENT

The second form the applicant is required to complete is a functional assessment for a child under 16 years of age. This form consists of two sections; the first section measures the child's functional ability in key functional domains, while section two addresses the behaviour and special care needs of the child. The form is structured in a checklist fashion.

The first section measures the child's functional ability in the following areas: communication – listening, reading and understanding, as well as talking, writing or signing; feeding and mealtime skills; hygiene and grooming skills; dressing skills; social and community skills and hand and body movement. A list of nine or

ten options is provided in each functional area, describing abilities or skills that a child should master at each developmental stage, from birth to late adolescence. For example, an option in the communication area reads: "Child responds to his or her own name." (Carer Allowance: 9, refer to Appendix A). The applicant is requested to choose one ability or skill out of the range, that best describes the child's functioning within each domain.

The second section describes various behavioural difficulties in a checklist format, e.g., anti-social behaviour, self-injury or violent behaviour. The applicant is required to indicate all the options that apply to the child concerned. Similarly with the special care needs question, a list of varying scenarios indicating special needs are provided, e.g., "Child has a tracheostomy."; "Child uses an electric wheelchair."; and "Child requires urinary catheterisation several times a day." (Carer Allowance: 8, refer to Appendix A). The applicant must indicate all the options that apply to the child. Finally, the applicant is required to complete a statement of consent, verifying that the correct information has been provided. It is clear that the CDAT is predominantly functional, and has a greater emphasis on the medical report than the caregiver's report.

THE SCORING PROCESS

The first step involves calculating the child's chronological age. Raw scores are assigned to each response in the THPs' and caregivers' questionnaires, based on the child's chronological age in relation to his or her functional age. A table is provided in the Child Disability Determination 2001 (Commonwealth of Australia, 2001a: 25) that illustrates this relationship and indicates a resultant score. Scores range form 0 to 10. This procedure calculates the scores to the responses from the first section of the caregiver's instrument.

The second section of the instrument records the special care needs and behaviour responses. Each option indicated here is given a score of 1; with the exception of special care need options indicating chronic lung disease or metabolic disorders, which are given a score of 2. The sum of the scores for each domain is computed as raw scores.

Hereafter, the raw scores are amended according to questionnaire weighting, milestone weighting and functional weighting. Additionally, an average of the feeding and mealtime skills, hygiene and grooming skills and dressing skills raw score is calculated and named the 'self care skills' score.

The questionnaire weighting involves dividing each score by 2, as a consequence of using responses from the THP and the caregiver. Milestone weighting involves multiplying all scores by 10/10, with the exception of the hygiene and grooming score, and the body movement score, which are multiplied by 9/10. This adjustment is necessary as these domains represent 9 milestones in their statements, while the others represent 10.

The functional weighting is applied to the scores of the receptive communication and special care needs domains. These scores are multiplied by 1.2, and 2, respectively. This is conducted to illustrate that a disability affecting these domains "... has a greater impact on the child and family." (Commonwealth of Australia, 2001: 2).

The weighted and adjusted scores are added together to obtain a THP score and caregiver score, and these scores are then utilised to determine the eligibility status of each child according to Australia's legislative criteria.

APPENDIX C: THE UNITED KINGDOM'S DISABILITY LIVING ALLOWANCE FOR A CHILD UNDER 16 – CLAIM FORM

notes

DLA1A **Child** *April 2001*

Important

Notes about claiming

Disability Living Allowance

for a child under 16

What is Disability Living Allowance?

Disability Living Allowance is a tax-free social security benefit for people with an illness or a disability who need

- help with getting around
- or help with personal care
- or help with both of these.

It is not affected by any money the child or the child's family might have as income, or by any savings they might have.

People can still claim Disability Living Allowance even if they do not actually get the help they need.

This is a claim pack specially for children. If you use this pack to claim for a person over 16, it may take longer to deal with the claim. You can get a claim pack for adults from the same place that you got this pack.

There are fixed amounts of money for Disability Living Allowance. The current rates are in leaflet **GL23** *Social Security Benefit Rates*. You can get this leaflet from any social security office.

When to claim

Claim straight away. People are normally only entitled to Disability Living Allowance when they have needed help for 3 months. But if you claim now, we can make sure that the child gets Disability Living Allowance as soon as they are entitled to it.

Invalid Care Allowance

If you are claiming the care component of Disability Living Allowance and there is someone looking after the child for 35 hours or more a week, they may be able to get **Invalid Care Allowance**. See form **DS700** for more information which you can get from your social security office. If someone thinks they may qualify for Invalid Care Allowance they should not delay putting in their claim, even if your claim for Disability Living Allowance has not been decided.

The questions in the claim pack

- Answer all the questions that apply to the child you are claiming for. And use the spaces to tell us in your own words as much as you can about the help they need. The more you can tell us the easier it is for us to get a clear picture of the child's problems. Do not worry if you are not sure how to spell anything or have to cross something out. But please do not use any correction fluid.

  Benefit the child gets because of this claim may be delayed if you have not filled in the claim form properly. If you find it difficult to fill in these forms, do not worry. One of our staff can help you. **Help and advice** on **page 3** of these notes tells you what help you can get filling in the forms.

- We know that a disability or illness can affect people more on one day and less on another – they have good days and bad days. When you tell us how the child's illnesses or disabilities affect them, tell us about the help they need **most** of the time. If you are not sure if we need to know about something, tell us anyway.

- We know that some of the questions we ask are very personal. And sometimes thinking about the things a child cannot do is upsetting. But we need to know these things to make sure that the child gets all the Disability Living Allowance they are entitled to.

- If there is not enough space on the form for everything you want to tell us, use a separate piece of paper and send it with the form. Make sure you put the child's name and reference number on any extra pieces of paper. If you do not know the reference number, use their date of birth.

If you want help filling in the claim pack or any part of it

- Ring the Benefit Enquiry Line for people with disabilities (BEL).
  The number is **0800 88 22 00**.

  The person you speak to may need to arrange for someone to phone you back. The person who calls you back is specially trained to help you fill in these forms. They will have a copy of the claim pack and they will go through it with you over the phone. Or they can fill in a claim pack for you.

  If they fill in the claim pack for you, they will send it to you. You can then check, sign and send it back. They can send you a completed claim pack in braille or large print. They will send you an envelope. It will not need a stamp.
- If you cannot use the phone, we can send someone to visit you. Please get in touch with your local Disability Benefit Centre. If you have a visit, it may take us longer to deal with your claim.
- You may be able to get help from an organisation that specialises in helping people with the child's illness or disability. Phone them and ask if they can help you.

Help and advice

If you want general advice about Disability Living Allowance or any other benefits you may be able to claim

- Ring the Benefit Enquiry Line for people with disabilities (BEL).
  The number is **0800 88 22 00**.

  The person you speak to will be able to give you general advice about Disability Living Allowance. And they can tell you about other organisations that may be able to help you.

  People with speech or hearing problems using a textphone can dial **0800 24 33 55**. If you do not have your own textphone system, they are available in some libraries and Citizens Advice Bureau.
- Get in touch with your social security office. You can find the phone number and address on the advert in the business numbers section of the phone book. Look under **Benefits Agency**.
- Get in touch with an advice centre like the Citizens Advice Bureau.

Problems with getting around

Children can only get Disability Living Allowance for help with getting around if they are **3 years old or over**. The rate of Disability Living Allowance that children get depends on the type of help or supervision they need and their age. If they need reminding or prompting or encouraging to walk, it depends on how much reminding, prompting or encouragement they need. There are 2 rates.

Lower rate

If the child is 5 years old or over and **any** of the following apply

- if the child can walk, but needs someone with them to make sure they are safe
- if the child can walk, but needs someone with them to help them find their way around in places they do not know well.

Remember that all children need some help and supervision when they are out of doors. The child you are claiming for must need **more** help or supervision than other children of the same age who do not have their particular problems.

Higher rate

The child is 3 years old or over and **any** of the following apply

- if the child is severely mentally impaired with severe behavioural problems and needs help with personal care both day and night
- if the child is deaf and blind and they need someone with them when they are outdoors, they must have a large amount of hearing loss and sight loss. But they do not have to be totally deaf and blind.
- if the child can only walk a short distance before they feel severe discomfort
- if the effort of walking could be dangerous for them
- if the child has had both legs amputated above the ankle or through the ankle, or was born without legs or feet
- if the child cannot walk at all.

Help with personal care

Children can only get Disability Living Allowance for help with personal care if they are **3 months old or over**. And remember that all children need some help or supervision. The child you are claiming for must need **more** help or supervision than other children of the same age who do not have their particular problems. The rate of Disability Living Allowance that children get depends on the amount of help or supervision they need, and on the sort of help or supervision they need. For example, they may need someone to keep an eye on them, or look after them while they are on dialysis. Or they may need help with things like washing, dressing, using the toilet, communicating with other people, or something like this. If they need reminding or prompting or encouraging to do things, it depends on how much reminding, prompting or encouragement they need.
There are 3 rates.

Lowest rate
- if the child needs **some** help during the day.

Middle rate
- if the child needs help during the day, **or**
- if they need help during the night.

Highest rate
- if the child needs help both day and night.

Special Rules

Some people can get Disability Living Allowance under the ***Special Rules***. These rules are explained on pages 7 and 8 and are called **Notes about claiming under the *Special Rules***.

About your National Insurance (NI) number

To link you with the right NI account and keep that account secure, we need proof of your identity and the right information from you. A NI number card on its own does not prove your identity. It is your responsibility to give us the right information to link you with the right account.

If you do not provide us with your NI number, there may be some delay in processing your application. If you do not have a NI number, or you have a temporary one beginning with the letters ZZ or TN, get in touch with your social security office, they will help you to apply for or trace a NI number. See **Help and advice** on page 3 of these notes.

Notes about

Claiming under the *Special Rules*

for a child under 16

About the Special Rules

Sadly, some children suffer from a terminal illness. We have therefore introduced ***Special Rules**** just for them so that they can get benefit quickly and easily.

Getting paid under the ***Special Rules*** means

- they get the highest rate each week for help with personal care
- they get paid straight away. There is no need to wait until the child has needed help for 3 months
- their claims are dealt with more quickly.

But children can only get money for help with getting around if they have difficulties with getting around.

Claiming for a child under the Special Rules

Please read the notes on the other side of this page. They tell you what to do if you want to claim for a child under the ***Special Rules***.

So that we can deal with the claim as quickly as possible, it is important that you send a doctor's **DS1500 Report** with the claim. These notes tell you how to get a **DS1500 Report**.

* The Special Rules apply to people who may not live longer than six months because of an illness. But it is, of course, impossible to say exactly how long a person will live.

How to claim for a child under the Special Rules

Section 1

- Please fill in **section 1** in this claim pack.
  Tick the box on page 5 to show that you are claiming for the child under the ***Special Rules***. If you do not tick this box, we cannot consider the claim under the ***Special Rules***.

Section 2

- If the child needs help with getting around, fill in page 1 to page 4. Then fill in page 23.
  Answer all the questions that apply to the child. Use the spaces to tell us in your own words as much as you can about the help that the child needs.
- If the child does not need help with getting around, please keep **section 2** for future use.

About the doctor's report

- Ask the child's doctor or specialist for a **DS1500 Report**.
  This is a report about the child's medical condition.
  You will not have to pay for it.
  You can ask the doctor's receptionist or a nurse or a social worker to arrange this for you. The doctor does not have to see the child.

  You should be given a **DS1500 Report** straight away. Ask for the report in a sealed envelope if you do not want anyone to see it.

What we want you to do

- Please send us
  - **section 1**
  - **section 2**, but only if the child needs help with getting around
  - **DS1500 Report**

  Please return this form as soon as possible.
  If you wait longer the child could lose money.

  Remember it will take a few days to reach us by post.

  If you cannot get the **DS1500 Report** in time, send us the claim straight away. Send the **DS1500 Report** as soon as you can.

section 1

Disability Living Allowance

Claim for a child under 16

DLA1A Child
section 1

Please complete and return this form as soon as possible as your date of claim will depend on the date we receive a completed claim form.

You may find it easier to fill in the forms in this claim pack if you read the Notes first. If you need help filling in this form, or any part of it, phone on 0800 88 22 00.

About the child

Surname

Other names

Any other surnames the child has had

Sex ☐ Male ☐ Female

Address where the child lives

Postcode

Previous address if the child has moved in the last two years

Postcode

The child's date of birth / /

Child reference number if you know it. Letters ☐ Numbers ☐ Letter ☐

What is the child's nationality?

We may get in touch with you for more information.

Has a claim been made for Disability Living Allowance for the child in the past 3 years? No ☐ Yes ☐ Not sure ☐

2

About the person claiming Disability Living Allowance for the child

Tell us about **yourself** here, not the child

Tell us your full name

Your date of birth

Your National Insurance (NI) number

Letters | Numbers | Letter

This helps us arrange payments quickly.

Your address

Postcode

Daytime phone number where we can contact you or leave a message.

Code | Number

Please tick the appropriate box

Home ☐ Work ☐ Mobile ☐ Fax ☐ Textphone ☐

What is your relationship to the child?
For example, parent, step-parent, foster parent, guardian, etc.

Do you receive Child Benefit for the child?

No ☐

Yes ☐

If someone else receives the Child Benefit, tell us their name.

What is the Child Benefit number for the child?
This is on the front of the Child Benefit order book or on letters about the benefit.

Where you want to be paid – you can choose

You can have the child's Disability Living Allowance paid straight into a bank or building society account, or you can collect it from a post office. Read the notes about the ways you can be paid on this page and the next page before you decide. If you want the benefit paid into a bank or building society, fill in the details on this page. If you want to collect the benefit from a post office, fill in the details on the next page

• Straight into a bank account or a building society account

- **This type of payment is the one we recommend** because it is safer – you do not have to carry cash around – and it saves trouble because the money is paid in automatically. It can also be withdrawn from a post office for a Girobank or National Savings bank account.
- **The account can be**
  - in your name, or in your partner's name if you have a partner. We use *partner* to mean a person you are married to or a person you live with as if you are married to them.
  - a joint account in your name and someone else's name
  - an account of a trustee, solicitor or accountant.
- **We will tell you when the money will be paid into the account for the first time. After that we will pay the money into the account at the end of every 4 weeks.**
- **If too much money is paid into the account**
  If you think that you have been paid too much money, please get in touch with us straight away. We will write and tell you if you need to pay the money back. If you have given us some new information and there is not enough time to change the amount you are paid, you will have to pay the extra money back. But if too much money is paid for some other reason, you may not have to pay it back.
- **If not enough money is paid into the account**
  If you think that you have not been paid enough money, please get in touch with us straight away. We will add the money we owe you on to the next payment. Or we will make a special payment. We will write and tell you what we are going to do.
- **What to do if you want the money to be paid into an account**
  Tell us about the account. You will find the information on the cheque book, on the pass book or on statements for the account.

For payment straight into an account

Whose name or names is the account in?

☐ **Bank account – not a mortgage account**

Name of bank

Branch name and address

Postcode

Bank sorting code number

Account number

☐ **Building Society savings or cheque account – not a mortgage account**

Name of building society

Type of account – For example current or deposit

Account number

Building society sorting code number

☐ **National Savings Bank investment account – not an ordinary account**

Account number

☐ **Girobank account**

Account number

Where you want to be paid – you can choose – continued

- **At a post office**
  - **Each payment will normally be for 4 weeks**
    But people claiming under the ***Special Rules*** can be paid weekly.
  - **What to do if you want to be paid at a post office**
    Just tell us on this page about the post office you want to use.
    If you cannot go to the post office yourself, someone else can go for you.
  - All social security benefit, allowance and pension payments can only be collected from one post office.

For payment at a post office

Tell us the address of the post office where you want to get the payment. If you are not sure of the address, ask the post office to stamp their address here.

Postcode

If you want someone to go to the post office for you regularly

Tell us about the person you want to go to the post office for you. They can collect your money for you if you are unable to go to the post office. You can still collect your own payments when you are able to go to the post office. You can only ask one person at any time to collect your payments. Please make sure you tell us about someone that you can trust.

Their surname Mr/Mrs/Miss/Ms

Their other names

Their date of birth / /

Their sex Male Female

Their National Insurance (NI) number We need this to arrange payments. Letters Numbers Letter

Their address

Postcode

Their daytime phone number where we can contact them. Code Number

Please tick appropriate box Home Work Mobile Fax Textphone

Tell us the address of the post office where you want to get the payment. If you are not sure of the address, ask the post office to stamp their address here.

Postcode

Declaration

This declaration is to be signed by the person you want to go to the post office for you.

I declare that the information on this page is correct and complete.

Signature

Date / /

Name of witness Mr/Mrs/Miss/Ms

Address of witness

Postcode

Signature of witness

This must not be the person you are asking to get your money for you.

Signature

Date / /

6

About Income Support and Jobseeker's Allowance

Please tell us if you are getting or waiting to hear about Income Support or Jobseeker's Allowance. Or tell us if someone else is getting or waiting to hear about Income Support or Jobseeker's Allowance for you. Tell us who is getting Income Support or Jobseeker's Allowance.

You ☐

Your partner ☐
We use *partner* to mean a person you are married to or a person you live with as if you are married to them.

Please tell us their name

Their National Insurance (NI) number

Are you or your partner waiting to hear about Income Support?

No ☐

Yes ☐

Are you or your partner waiting to hear about Jobseeker's Allowance?

No ☐

Yes ☐

About the child's illnesses or disabilities

What are the child's illnesses or disabilities?
Just tell us the names of the child's main illnesses or disabilities. We will ask you how these affect the child in **section 2** of this claim pack.

If medicines, tablets or other medical treatments are prescribed for the child's illnesses or disabilities, tell us about them here.
This information will be on the printed label on front of the child's medicine bottle.

Has the child had a medical examination in the last six months in connection with any other social security benefit?

No ☐

Yes ☐ If yes, please tell us which benefit?

Claiming under the *Special Rules*

The ***Special Rules*** and the **DS1500 Report** are explained in the **Notes about Claiming under the *Special Rules***.

Are you claiming for the child under the *Special Rules*?

No ☐

Yes ☐

More about the child

Does the child normally live in Great Britain?
Great Britain is England, Scotland and Wales.

No ☐

Yes ☐ Where do they live? **Please tick appropriate box**

England ☐ Scotland ☐ Wales ☐

If you live in Wales and would like to receive future communications in Welsh, please tick this box ☐

Has the child been abroad in the last 12 months?

No ☐

Yes ☐ Tell us when they went abroad.

From / / To / /

Tell us where they went.

Tell us why they went.

Do either of the parents or step-parents of the child have any income from abroad that they do not have to pay UK tax on?
The UK is England, Scotland, Wales and Northern Ireland.

No ☐

Yes ☐ We will write to you about this. But please still fill in the rest of this form.

The child's school/nursery

Name of child's school/nursery

Address

Postcode

Phone number

Code Number

Contact
This could be a teacher for example

For children in hospital now

Is the child in hospital now?

No ☐ Go to the next question under the thick line.

Yes ☐

When did the child go into hospital?

/ /

When will they leave hospital, if you know this?

/ /

Please tell us the full name and address of the hospital. Tell us the name or number of the ward if you know it.

Postcode

Hospital phone number, if you know it.

Code Number

While the child is in hospital is the NHS paying for their stay and treatment?

No ☐ Yes ☐ Not sure ☐

For children in residential care now

Residential care includes – a residential school or college, a children's home, hospice care, respite care or anywhere like this.

Is the child in residential care now?

No ☐ Go to **Page 10**.

Yes ☐

Please tell us the full name and address where the child is staying.

Postcode

Phone number, if you know it.

Code Number

When did the child first start to live in residential care?

/ /

Does a local authority, a health authority, an NHS trust, or a government department pay any of the costs for the child to live there?

No ☐ Not sure ☐

Yes ☐ Which authority, NHS trust or government department pays?

10

For children who have been in hospital or residential care

Has the child been in hospital or residential care in the past 13 weeks?

No ☐ Go to the next question under the thick line.

Yes ☐ Tell us when they went in. If they have come out of hospital or residential care, please tell us when this was.

in / /

out / /

Please tell us the full name and address of where the child was staying.

Postcode

Phone number, if you know it.

Code Number

Who would you like to tell us about the child's illnesses or disabilities?

This could be
- a teacher
- a nurse, a health visitor, a physiotherapist, a speech therapist, or an occupational therapist
- someone from the Social Services or the Social Work Department
- a doctor.

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code Number

What is their job?

When did they last see the child?

The child's family doctor or GP

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code Number

When did the child last see their doctor about their illnesses or disabilities?

The child's hospital doctor or specialist

Tell us about any hospital doctor or specialist the child has seen in the last 12 months because of their illnesses or disabilities. This might be a doctor at a child development centre. If you want to tell us about more than one person, give us the details on an extra piece of paper and send it with this form.

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code Number

The child's record number, if you know it.

When did the child last see their hospital doctor or specialist?

The child's present illness/disability they are seeing a hospital doctor or specialist for

For children on kidney dialysis

Tell us about the hospital that arranges the dialysis, so we can contact them.

Hospital address

Postcode

Hospital phone number, if you know it.

Code Number

Hospital record number, if you know it.

Only for people claiming for a child under the *Special Rules*

1 Please check that you have answered all the questions on this form that apply to you or to the child you are claiming for. Check that you have ticked the box on page 5.

2 **Sign the Declaration on page 13.**

3 If you want to claim Disability Living Allowance for the child for help with getting around
- read the **Notes about claiming Disability Living Allowance**, where we explain what we mean by help with getting around
- go to **section 2** in this claim pack. Fill in **About the child** which starts on page 1. And fill in page 1 to page 4. Then go to page 23 and fill in this page.

Send this form to us. Send it with the **DS1500 Report** from the child's doctor.

Please return everything to us as soon as possible, as your date of claim will be taken as the date we receive this section. If you wait longer you could lose money.

If you cannot get your **DS1500 Report** straight away, do not wait to send us the claim.

What to do now

Tick the box that applies to you. Only tick **one** box.

1 **If you can, send us both sections together.**
This will help us to deal with the claim quickly.
If you are sending **section 2** with this form, tick this box. ☐ Now sign the Declaration

2 **If you cannot send both sections together,**
send **section 1** now, and **section 2** when you have filled it in.
If you are going to send **section 2** later, tick this box. ☐ Now sign the Declaration

3 **If you have difficulty filling in section 2,** you can phone on **0800 88 22 00**. If you cannot use the phone, we can send someone to visit you to help you fill in **section 2**, tick this box. ☐ Now sign the Declaration

4 **If you do not want to fill in section 2,** you can ask for a doctor to visit. The doctor will normally examine the child.
If you would like a doctor to visit, tick this box. ☐ Now sign the Declaration

Remember – if you leave section 2 with someone else so they can fill in the statement on page 24, send section 1 to us straight away. Do not wait until you get section 2 back. We will tell you when we have received section 1. If you do not hear from us within 2 weeks of when you send us section 1, please get in touch.

Declaration

- **I declare**
  that the information I have given on this form is correct and complete.
- **I declare**
  that if I have said that I want Disability Living Allowance paid straight into an account, I have read and understood the notes on **page 3** of this form about being paid in this way.
- **I agree**
  that the Department of Social Security or any doctor, or doctor providing medical services on behalf of an organisation, approved by the Secretary of State may ask any of the people or places mentioned on this form for any information which is needed to deal with
  - this claim for benefit or
  - any request for this claim to be looked at again

  and that the information may be given to that doctor or to the Department.
- **I understand**
  that the Department may use the information which it has now or may get in the future to decide whether this child is entitled to
  - the benefit I am claiming for them now
  - any other benefit I have claimed for them
  - any other benefit I may claim for them in the future.

Warning – to knowingly give false information may result in prosecution.

Signature

Date / /

How we collect and use information

The Department of Social Security (DSS) collects information for social security, child support, vaccine damage and war pensions purposes. The information we collect about you will depend on the nature of your business with us, but may be used for any of the Department's purposes. We may check information provided by you, or information about you provided by a third party, with other information held by us.

We may also get information about you from certain third parties, or give information to them to check the accuracy of information, to prevent crime or detect crime, or to protect public funds in other ways, as permitted by law. These third parties include other government departments and local authorities.

We will not disclose information about you to anyone outside the DSS unless the law permits us to.

DSS is the Data Controller for the purposes of the Data Protection Act. If you want to know more about what information we have about you, or the way we use information, you can ask for details at any DSS office.

Please turn over ▶

14

Statement from someone else who knows the child

Please ask someone who knows how the child's illness or disability affects them to sign this statement. This could be anyone who knows the child well. For example, a carer, relative, friend, professional health care worker or someone like this. They do not need to look at the answers on this form.

I know *(child's name)* and they have a disability or illness.

Signature

Date / /

Name and address

Postcode

What is your relationship to the child this form is about?

How the child's
illness or disability affects them

If you find it difficult to fill in section 2 do not worry. Phone on **0800 88 22 00** and we will help you. **Help and advice** on page 3 of the **Notes about claiming Disability Living Allowance** tells you how else we can help you.

Your answers in this section will help us to get a clear picture of how the child's illness or disability affects them. This will help us to decide if they can get Disability Living Allowance. Before you fill in this form, you may find it useful to

- have a look through the form to see what we need to know
- keep a record for a day or two of how the child's illness or disability affects them.

If there is not enough space on the form for your answers, you can write on a separate piece of paper and send it with the form. If you use extra pieces of paper, make sure we can tell which question you are answering.

Statement from a person who knows the child
We ask you for a statement from someone who knows how the child's illnesses or disabilities affect them. This is on page 26 of this form. Try to get this statement filled in. It will help us to deal with the claim quickly. But if you cannot get the statement filled in, do not worry – we will normally write to someone who can tell us about the child's illness or disability. But it may take longer to deal with the claim.

For people claiming under the *Special Rules*

Remember only fill in this form if you want to claim Disability Living Allowance for a child for help with getting around, otherwise please keep **section 2** for future use. We do not need to know about the help that the child needs with personal care.

Fill in pages 1 to 4. Then go to page 25 and fill in this page.

About the child

Please fill in these details again, so that we can keep all the papers together.

The child's full name and address

Postcode

Date of birth / /

Child reference number if you know it.

Letters | Numbers | Letter

About the child – continued

Please tick **all** the boxes that apply to the child. Tell us if the child

is blind or partially sighted	☐	Partially sighted means that they have problems with their eyesight even when wearing glasses or contact lenses.
has problems with hearing even with a hearing aid	☐	
has problems with speech or language which affects communication with other people	☐	
is both deaf and blind	☐	To get help because of deafness and blindness the child must have a large amount of loss of hearing and sight. But they do not have to be totally deaf and blind.
has physical disabilities	☐	
was born without legs or feet or has had both legs amputated above or through the ankle	☐	
has a learning difficulty	☐	
has a mental health problem	☐	
has both a severe learning disability and severe behavioural problems	☐	
has a long term illness	☐	

About Disability Living Allowance for children

All children need some help or supervision. For a child to get Disability Living Allowance they must need **more** help or supervision than other children of the same age who do not have their illnesses or disabilities. Tell us in this form about the **extra** help the child needs. Tell us as much as you can about the ways the child's illnesses or disabilities affect them. The more you tell us, the easier it is for us to get a clear picture of the type of help the child needs. You can claim Disability Living Allowance for children as soon as they are born, but we cannot start to pay until they are **3 months old**.

We know that illnesses or disabilities can affect people more on one day than another – they have **good days and bad days**. If the child you are claiming for has good days and bad days, try to tell us about the problems they have **most** of the time. If you are not sure if we need to know something, tell us anyway.

We know that some of the questions will be difficult to answer, especially for babies and very young children, but please try to tell us as much as you can.

Walking outdoors

By this we mean walking on reasonably level ground, not up or down hills or slopes. You can only get Disability Living Allowance for help with getting around at the higher rate if the child you are claiming for is **3 years old or over**.

You cannot get Disability Living Allowance for help with getting around at the lower rate until the child is **5 years old or over**.

Does the child have difficulties walking?
This may be because
- they cannot walk at all
- of an amputation
- they were born with a deformity of the spine, legs or feet, or something like this
- of paralysis, weakness or stiffness
- walking makes them breathless or gives them pain or discomfort
- of a heart condition
- they refuse to walk.

No ☐ Go to **Page 4**.

Yes ☐

Tell us about the difficulties they have with walking and about any equipment they use to help them.
Tell us here if there is anything about the way the child walks that causes difficulties. For example, if they have poor co-ordination, bad balance or a poor manner of walking. Tell us if the effort of walking might be dangerous for the child and why this might be. Equipment might be crutches, a walking stick or walking frame, an artificial leg, callipers, splints, a rolator, or something like this.

How many days a week does the child have these difficulties?

days a week

How far can the child walk before they have to stop because of severe discomfort?
For example, it may be too painful for them to go on, or they may need to stop and rest.

metres/yards

How long does it take them to walk this far?

minutes

If the child needs someone with them when they are outdoors

Does the child need to have someone with them when they are outdoors in places they do not know well?

For example, they may need someone to look after them because

- they are blind or partially sighted
- they are deaf or hearing impaired
- they might fall
- they have behavioural problems or a severe learning disability
- they may forget where they are going, or wander off
- they need a lot of encouragement to walk
- they might put themselves or other people in danger.

No ☐ Go to Page 5.

Yes ☐

Remember – the child must need **more** help than a child of the same age who does not have their illness or disability.

Tell us why the child needs someone with them when they are outdoors in places they do not know well.

For example, they may be easily confused or taken advantage of.

Remember – if you need help filling in this form, or any part of it, phone on **0800 88 22 00**.

Someone keeping an eye on the child

All children need someone to keep an eye on them to make sure that they are safe. Answer the questions on this page if the child you are claiming for needs **more** supervision during the day or night than other children of the same age who do not have their illness or disability. By **night** we mean when the household has closed down at the end of the day.

Does the child need someone to keep an eye on them?
For example, because they
- have no sense of danger and might hurt themselves or someone else
- might wander about
- have behavioural problems
- cannot hear or see or respond to danger signs
- need someone to monitor their medical condition or diet.

No ☐ Go to **Page 6.**

Yes ☐

Why the child needs someone with them.
During the day

Why the child needs someone awake with them.
During the night

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many days a week does the child need someone with them?

days a week

How much of the day do they need someone with them?

Roughly how long do they need someone with them each time during the day?
We know this may be difficult, but please try to tell us in minutes.

minutes

How many nights a week does the child need someone to be awake with them?

nights a week

How much of the night does someone have to be awake with them?

Roughly how long do they need someone awake with them each time during the night?
We know this may be difficult, but please try to tell us in minutes.

minutes

About the child's development

We know that all children develop at different rates, but some illnesses or disabilities can have a marked effect on how a child develops. Tell us if the child you are claiming for has suffered a delay in their development.

Does the child have a delay in their development of physical or sensory skills?
For example,
- using their hands
- hearing or talking
- sitting, standing or walking.

Or something else.

No ☐ Go to the next question under the thick line.

Yes ☐ Tell us about the help they need.

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Roughly how many times a day does the child need help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Does the child have a delay in their development of learning skills?
For example,
- understanding the world around them
- following instructions
- developing daily living skills.

Or something else.

No ☐ Go to **Page 7.**

Yes ☐ Tell us about the help they need.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Roughly how many times a day does the child need help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

About the child's development – continued

Does the child have a delay in their development of social skills?
For example,
- interacting with others
- communicating with others.

Or something else.

No ☐ Go to the next question under the thick line.

Yes ☐ Tell us about the help they need.

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Roughly how many times a day does the child need help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Does someone need to help the child develop through play?
For example, encouraging
- age appropriate play
- stimulating play.

Or something else.

No ☐ Go to **Page 8.**

Yes ☐ Tell us about the help they need.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

Roughly how many times a day does the child need help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Waking, getting up and going to bed

Does the child have difficulties waking, getting up or going to bed?
For example, they may need help with things like
- getting into or out of bed
- settling in bed
- staying in bed.

Or help with something else.

No ☐
Yes ☐

Remember - the child must need **more** help than a child of the same age who does not have their illness or disability.

Does someone have to wake the child up, or tell or encourage them to get up or go to bed?

No ☐
Yes ☐

Tell us about the help the child needs to wake up or get up or go to bed.
Tell us about any equipment the child uses and how it helps them.

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take the child to get out of bed or into bed?
We know this may be difficult, but please try to tell us in minutes.

minutes

Remember – if you need help filling in this form, or any part of it, phone on **0800 88 22 00**.

Washing and bathing

Does the child have difficulties washing, or having a bath or shower?
For example, they may need help with things like
- cleaning their teeth
- washing their hair
- getting into or out of the bath or shower
- physical support
- coping with periods
- keeping safe

Or help with something else.

No ☐

Yes ☐

Remember – the child must need **more** help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to wash or have a bath or shower?

No ☐

Yes ☐

Tell us about the help or encouragement the child needs washing or having a bath or shower. If they have bed baths, tell us about this here. Tell us about any equipment the child uses and how it helps them.

How many days a week does the child need this help?

days a week

How many times a day does the child need help with washing or having a bath or shower?

times a day

Roughly how long does the child take to have a bath or shower?
We know this may be difficult, but please try to tell us in minutes

minutes

Getting dressed or undressed

Does the child have difficulties getting dressed or undressed?
For example, they may
- need someone to help them, or it may take a long time
- have poor co-ordination
- have no control over their arms or legs
- not be able to judge appropriate clothes.

Or they may need help with something else.

No ☐
Yes ☐

Remember – the child must need **more** help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to get dressed or undressed?

No ☐
Yes ☐

Tell us about the help or encouragement the child needs getting dressed or undressed. Tell us about any equipment the child uses and how it helps them.

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take the child to get dressed or undressed?
We know this may be difficult, but please try to tell us in minutes.

minutes

Remember – if you need help filling in this form, or any part of it, phone on **0800 88 22 00**.

Help with toilet needs

We know these are very personal questions, but this information will help us to decide about the child's claim.

Does the child have difficulties coping with their toilet needs?
For example,
- getting to the toilet and using the toilet
- using something like a nappy, commode, bedpan or bottle instead of the toilet
- using or changing incontinence aids
- catheterisation or bladder expression
- using enemas or suppositories.

No ☐
Yes ☐

Does someone have to tell or encourage the child to attend to their toilet needs?

No ☐
Yes ☐

Tell us about the help or encouragement the child needs and any equipment they use.
During the day

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help or encouragement the child needs and any equipment they use.
During the night

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Communicating with other people

Does the child need help understanding other people?
For example, they need someone to
- help with lip reading
- explain what people mean
- interpret sign language.

No ☐ Go to the next question under the thick line.

Yes ☐ Tell us about this.

Tell us about the child's difficulties understanding other people. Tell us about anything the child needs to help them understand other people, and how useful this is. Tell us if they need to have physical contact or some other sign to attract their attention.

If the next 2 questions are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need someone to help them understand other people?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Does the child need help being understood by other people?
For example,
- because of a language disorder or a physical speech problem
- someone has to interpret the child's language, signs or gestures.

No ☐ Go to **Page 13.**

Yes ☐ Tell us about this.

Tell us about the child's difficulties being understood by other people. Tell us about any equipment the child uses to help them, and how useful this is.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need help to make themselves understood by other people?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Communicating with other people – continued

Is the child unwilling to communicate with other people?
For example, because of
- difficult or withdrawn behaviour
- frustration or stress
- a communication disorder.

Or something like this.

No ☐ Go to **Page 14.**

Yes ☐ Tell us about this.

Tell us about the encouragement the child needs to help them communicate with other people. Tell us about any equipment the child uses to help them and how useful this is.

If the rest of the questions on this page are difficult to answer because of the child's condition, do not worry. You can tell us more about this later.

How many times a day do they need help to communicate with other people?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Eating and drinking

Does the child have difficulties eating or drinking?
For example, they need help
- cutting up food or being fed
- with a specialised feeding method.

Or with something else.

No ☐
Yes ☐

Does someone have to tell or encourage the child to eat or drink?

No ☐
Yes ☐

Tell us about the help or encouragement the child needs, and any equipment they use.

During the day

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help or encouragement the child needs, and any equipment they use.

During the night

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Help with medication

Does the child need help with medication?
For example,
- taking tablets or medicines
- having injections
- using an inhaler or nebuliser
- applying creams
- they do not co-operate with their treatment.

No ☐ Go to **Page 16.**

Yes ☐ Tell us about this.

Tell us about the help or encouragement the child needs with medication.

During the day

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help or encouragement the child needs with medication.

During the night

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Help with therapy

Does the child need help with therapy?
Therapy may be done by a therapist or by someone else. It may be at home or somewhere else. It may involve exercises, routines or methods designed to help the child develop. For examp-e,

- physiotherapy
- speech therapy
- play therapy

Or something else

No ☐ Go to Page 17.

Yes ☐ Tell us about this.

Tell us about the help or encouragement the child needs with therapy.

During the day

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help or encouragement the child needs with therapy.

During the night

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Help with medical equipment

Does the child need help with medical equipment?
For example,
- colostomy or catheter care
- tracheostomy care
- using splints, gaiters or special clothing.

Or something else.

No ☐ Go to **Page 18.**

Yes ☐ Tell us about this.

Tell us about the help or encouragement the child needs with medical equipment.

During the day

How many days a week does the child need this help?

days a week

How many times a day does the child need this help?

times a day

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help or encouragement the child needs with medical equipment.

During the night

How many nights a week does the child need this help?

nights a week

How many times a night does the child need this help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes

minutes

Remember – if you need help filling in this form, or any part of it, phone on **0800 88 22 00**.

Blackouts, fits, seizures or something like this

Does the child have blackouts, fits, seizures or something like this?
For example, because of
- epilepsy
- diabetes.

No ☐ Go to Page 19.

Yes ☐ Tell us about this.

Tell us what happens.
We need to know
- what happens before they have a blackout, fit or seizure
- if they get any warning of what is going to happen
- what happens during the fit or seizure
- if they lose consciousness or if their limbs shake, or if they bite their tongue or are incontinent
- what happens after a fit or seizure, if they need to sleep or if they are confused.

Tell us anything that will help us get a clear picture of what happens to the child if they have a blackout, fit or seizure.

Tell us about the help the child needs.

During the day

Tell us roughly how often this happens.

Roughly how long does the child need help each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Tell us about the help the child needs.

During the night

Tell us roughly how often this happens.

Roughly how long does the child need help each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

The child's mental health

Does the child have difficulties because of the way they feel?

For example, they may sometimes

- get anxious or panicky
- get upset or frustrated
- feel someone may harm them
- try to harm themselves
- be verbally or physically aggressive
- try to damage things
- be impulsive or destructive
- feel they cannot cope with even the slightest change to their daily routine.

Or something else.

No ☐ Go to Page 20.

Yes ☐ Tell us about this.

Tell us about the help the child needs and the things the child does because of their mental health problems.

Tell us roughly how often this happens, and how long the child needs help when it happens.

Remember - if you need help filling in this form, or any part of it, phone on **0800 88 22 00**.

Movement and co-ordination

Does the child have difficulties with movement and co-ordination?
For example, they
- cannot move at all
- suffer pain when they move
- may injure themselves if they move
- cannot co-ordinate movements of their arms or legs

Or something else.

No ☐ Go to the next question under the thick line.

Yes ☐ Tell us about this.

Tell us about the help the child needs with movement and co-ordination.

Moving about indoors

Does the child have difficulties moving about indoors?
For example, with things like
- getting out of a chair
- walking around indoors
- going up or down stairs
- using a wheelchair or Major Buggy
- transferring from a wheelchair or Major Buggy
- having to be carried.

No ☐

Yes ☐

Remember – the child must need more help than a child of the same age who does not have their illness or disability.

Does someone have to tell or encourage the child to move about indoors?

No ☐

Yes ☐

Tell us about any help or encouragement the child needs moving about indoors. Tell us about any ways the child's home has been adapted, or about any equipment they use to help them move about indoors. This could be a wheelchair, a frame, a stairlift, or something like this.

When the child is in bed at night

By **night** we mean when the household has closed down at the end of the day.

Does the child need help when they are in bed at night?
For example, they may need help with things like
- changing sheets or nightclothes
- getting bedclothes back on the bed if they fall off
- turning over
- resettling to sleep after waking because of night terrors or irregular sleep patterns
- getting back into bed after falling out
- settling and staying in bed.

Or something else.

No ☐ Go to **Page 22.**

Yes ☐ Tell us about this.

Remember – the child must need **more** help than a child of the same age who does not have their illness or disability.

Tell us about any help the child needs when they are in bed at night.

How many nights a week does the child need help?

nights a week

How many times a night does the child need help?

times a night

Roughly how long does it take each time?
We know this may be difficult, but please try to tell us in minutes.

minutes

Help the child needs when they go out during the day or in the evening

Please tell us in this part about the help the child needs **from another person** at home or when they go out. For example, this can be help with things like social and religious activities, interests and hobbies.

Remember – they can be helped in lots of different ways. Someone speaking to them can count as help if they

- **tell them or encourage them to do things**
- **tell them how to do things**
- **tell them if there is danger.**

Even someone reading to them or helping them to communicate with other people can count as help. For example, they may need someone to interpret their sign language for other people. Or they may only be able to make themself understood to someone who knows them well, who needs to interpret what they are saying for other people.
You should tell us about the help they need even if they do not actually get that help.

We want you to tell us about each of the different things they usually do or would do if they had the help they need. Use a separate box to tell us about each thing. We have given you three sets of boxes, but you do not have to fill in every set unless you need to tell us about 3 different things. If you want to tell us about more than 3 things, use a separate sheet of paper and send it to us with this form.

What they do or would do if they had the help they need

When they go out during the day or evening

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

What they do or would do if they had the help they need

At home

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

Help the child needs when they go out during the day or in the evening – continued

What they do or would do if they had the help they need

When they go out during the day or evening

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

What they do or would do if they had the help they need

At home

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

What they do or would do if they had the help they need

When they go out during the day or evening

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

What they do or would do if they had the help they need

At home

How many days a week?

days a week

How many times a day?

times a day

How long do they usually need help for each time?

What help do they need from another person?

Anything else about the way the child is affected by their illnesses or disabilities

Tell us about any ways that the child's illnesses or disabilities affect them that you have not been able to put anywhere else on this form.

For example, the child may need special help at school or nursery. Or there may be places on this form where the questions have been difficult to answer, and you want to tell us more about the help the child needs. Or you may want to tell us if the child's condition changes from day to day, which means that the amount of help they need varies.

Tell us anything that you think will help us get a picture of how the child is affected by their illnesses or disabilities.

About the child's condition

Tell us when the child started to have the problems you have told us about.
If the problems with getting around and with personal care started on different dates, tell us about this. Tell us the exact dates if you can. But if you cannot remember, tell us roughly when this was.

/ /

Do you think the child will have the difficulties you have told us about for the next 6 months or longer?
Tick one of these boxes.

No ☐

Yes ☐

Declaration

Please sign this form here.
Even if you have already signed **section 1**, still sign this form here.

The information I have given about the way the child's illnesses or disabilities affect them is correct and complete.

Warning – to knowingly give false information may result in prosecution.

Signature

Date

/ /

What to do now

Get the statement on the next page filled in if you can. It will help us deal with the claim quickly. If you cannot get the statement filled in, do not worry. We will normally write to the child's doctor or to someone else who can tell us about their illness or disability. But it may take longer to deal with the claim.

Statement from a person who knows the child

People who can fill in this statement

This statement will help us deal with the claim quickly.
Please ask a person who knows how the child's illnesses or disabilities affect them to fill in this statement. This could be someone else who looks after the child, a carer, a relative, a friend, a social worker, a community psychiatric nurse, a teacher, a therapist, a nurse, a doctor or specialist, **or anyone who knows the child well.**

Notes for people filling in this statement

Please fill in this statement straight away and give the form back to the person who asked you to fill it in. Please fill it in from your own knowledge – **you do not need to look at their answers on this form.**

Please fill in the name and address of the child this form is about.

Child's name

Child's address

Postcode

Tell us when you last saw the child

Please fill in your own name and address.

Your full name

Your address

Postcode

Your phone number

Code Number

Tell us your job or profession or relationship to the child this form is about.

Please tell us what their illnesses and disabilities are, and how they are affected by them.

Your signature

Date

/ /

APPENDIX D: THE UNITED KINGDOM'S DISABILITY LIVING ALLOWANCE FOR A CHILD UNDER 16 - CLAIM FORM

SUMMARY OF SECTIONS 1 AND 2

SUMMARY OF SECTION 1

Section 1 requests details regarding:

- Other social security benefits received by the child or carer;
- Payment details, as benefit payments are directly paid into bank accounts and the like;
- The child's main disabilities or illnesses;
- Details about the child's place of residence, schooling, periods of hospitalisation and residential care;
- Contact details of another informant for verification of child's illness or disability, e.g., teacher, health professional, social service worker or doctor;
- Contact details of the child's family doctor and hospital or treatment doctor or specialist; and
- Signed declaration of the applicant and signed statement from another person who is familiar with the child's disability or illness, e.g., carer, relative or friend.

(United Kingdom Social Security Benefits Agency, Disability Living Allowance for a child under 16: claim form, Appendix C)

SUMMARY OF SECTION 2

Measures of time are contained in questions such as:

- How many days a week does the child experience these difficulties?;
- How much of the day and how much of the night does the child need someone with him or her?;
- Roughly how many times a day does the child need this help?; and
- Roughly how long (in minutes) does it take each time to help the child?

(United Kingdom Social Security Benefits Agency, Disability Living Allowance for a child under 16: claim form, Appendix C)

Section 2 requests a description of:

- The type of disability or illness – the carer is requested to identify which conditions affects the child from a checklist of conditions;

- The child's difficulties with walking, the child's use of assistive devices to aid in walking, and the nature and frequency of these difficulties, e.g., the child's need for supervision when the child is walking outdoors;
- The child's need for supervision during the day and night;
- The assistance the child needs as a result of a delay in their development of physical or sensory skills, learning skills and social skills;
- The assistance a child needs to help him or her to develop through play;
- The assistance or encouragement a child needs and their use of assistive devices to:
  - wake up, get up or go to bed
  - wash, have a bath or shower, including activities like brushing teeth
  - dress or undress
  - attend to their toilet needs during the day and night;
- The child's difficulties with understanding other people and being understood by other people, including their need for assistance or assistive devices to facilitate their communication;
- The encouragement a child needs to help them communicate with others, including any equipment used;
- The assistance or encouragement the child requires, and his or her use of equipment to:
  - eat or drink
  - administer medication
  - engage in therapy;
- The assistance a child requires if a child experiences blackouts, fits or seizures;
- The child's difficulties because of their mental health condition, specifying the assistance the child requires and the child's actions;
- The assistance or encouragement a child requires with movement and co-ordination;
- The assistance or encouragement a child requires to be mobile indoors, specifying whether the child's home has been adapted and what equipment the child uses to assist in their indoor mobility;
- The assistance a child requires when he or she is in bed at night, e.g., if the child needs to be turned over;

- The assistance a child requires from another person at home or when they go out, e.g., help with social and religious activities;
- The applicant is given an opportunity to provide additional information about how the disability or illness affects the child, other than that described previously;
- The applicant is requested to specify when the child started to have the difficulties described, and the applicant is then asked whether they perceive the child will continue to have these difficulties for the next 6 months; and
- Signed declaration of the applicant and signed statement from another person who is familiar with the child's disability or illness, e.g., carer, relative or friend.

(United Kingdom Social Security Benefits Agency, Disability Living Allowance for a child under 16: claim form, Appendix C)

APPENDIX E: THE SOUTH AFRICAN CARE DEPENDENCY GRANT – MEDICAL CERTIFICATE

CARE - DEPENDENCY GRANT

MEDICAL CERTIFICATE: CARE - DEPENDENT CHILD

A. TO BE COMPLETED BY ADMINISTRATIVE OFFICER

Reference number _____ Identity number _____

APPLICANT

Surname _____

Full names _____

Address _____ Postal address _____

_____ _____

_____ _____

FIRST APPLICATION		RE-APPLICATION		REVIEW	

CARE DEPENDENT CHILD

Identity number _____ Date of Birth _____

Surname _____

Full names _____

B. REFERRAL LETTER

CLINIC/ PHYSICIAN/MEDICAL ATTENDANT

PERMISSION

I, the undersigned herewith give my permission that the care - dependent child's medical history be made available for the purpose of an application for a care - dependency grant.

.....
Signature of applicant

MEDICAL HISTORY IN ORDER TO APPLY FOR A CARE - DEPENDENCY GRANT

To enable the abovementioned to apply for a care - dependency grant for care dependent children, it would be appreciated if you could supply the State Medical Officer (District Surgeon) with a medical report in respect of the child concerned.

Medical report as requested attached for your information.

.....
Signature Medical Practitioner/Hospital

C. TO BE COMPLETED AND SIGNED BY STATE MEDICAL OFFICER

HAS CARE - DEPENDENT CHILD BEEN IDENTIFIED BY IDENTITY DOCUMENT?

YES		NO	

If no, state reason _____

MEDICAL EXAMINATION

0 = VERY POOR
1 = POOR
2 = FAIR
3 = SATISFACTORY
4 = GOOD
5 = VERY GOOD

1	Cardiovascular	0 1 2 3 4 5
2	Respiratory	0 1 2 3 4 5
3	Musculo-Skeletal	0 1 2 3 4 5
4	Nervous system	0 1 2 3 4 5
5	Vision	0 1 2 3 4 5
6	Hearing	0 1 2 3 4 5
7	Comprehension	0 1 2 3 4 5
8	Mental condition	0 1 2 3 4 5
9	Epilepsy	0 1 2 3 4 5
10	Other	0 1 2 3 4 5

Diagnosis _____

Prognosis _____

MEDICAL OFFICER'S OPINION

i. Is the mental and/or physical disability?

SEVERE		MILD		NOT DISABLED	

ii. Special treatment and/or rehabilitation recommended _____

iii. Special training/education recommended _____

iv. Does the child require permanent home care, due to his/her severe mental or physical disabilty? _____

_____

_____

v. Re-evaluation recommended at age of four years _____

_____

_____

OFFICIAL STAMP

Signature .....

PRINT _____ Date .....

Telephone number _____ Dialing code _____

D. FUNCTIONAL ASSESSMENT
(Age: 4 Years)

1. MOBILITY:

1.1	Sitting	yes	no
1.2	Crawling	yes	no
1.3	Standing - alone	yes	no
1.4	Walking - independently	yes	no
1.5	Running - well coordinated	yes	no

Your opinion: _____

_____

2. SELF CARE

1 = TOTAL DEPENDENCY
3 = 50 % DEPENDENCY
5 = INDEPENDENT

2.1	Eating	1	2	3	4	5
2.2	Grooming	1	2	3	4	5
2.3	Bathing	1	2	3	4	5
2.4	Dressing	1	2	3	4	5
2.5	Toiletting	1	2	3	4	5

Your opinion: _____

_____

3. COMMUNICATION:

3.1 Comprehension
Ask the child to fetch the book on the table and to bring it to you.

_____

_____

3.2 Expression
Ask the child to tell you what he did yesterday.

_____

_____

3.3 Speech intelligibility
Listen to what the child is telling you in response to the question in 3.2.

_____

_____

4. PSYCHOSOCIAL ADJUSTMENT:

4.1 Social interaction
Observe how the child interacts with you, his mother, or other children in the vicinity.

_____

_____

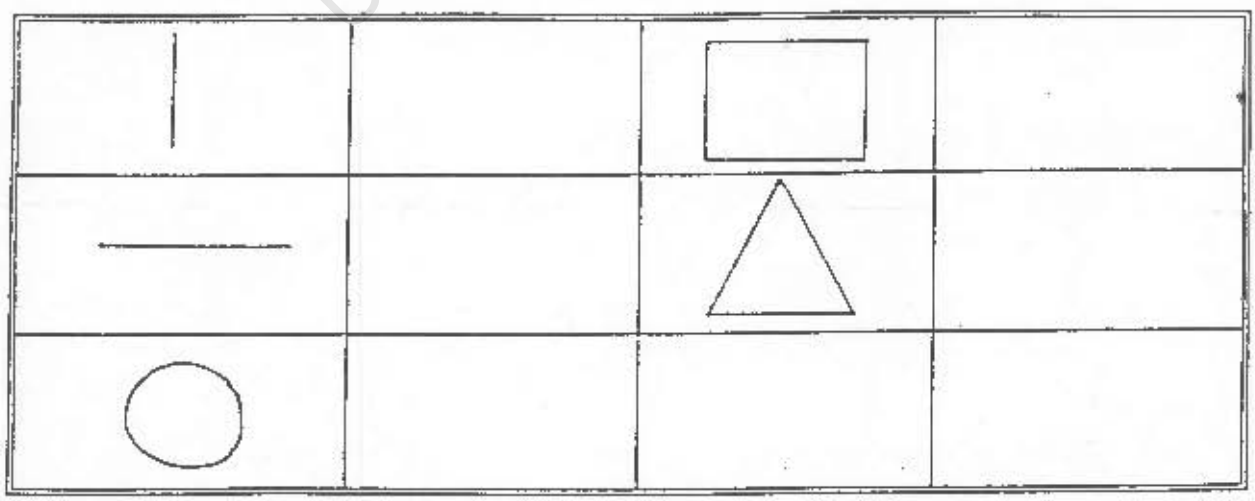
4.2 Emotional response
Ask the mother how the child reacts to anger or frustration.
Eg. Tantrums, Aggression, Withdrawal

_____

_____

5. COGNITIVE FUNCTIONING:

5.1 Copying
Ask the child to copy the following:



5.2 Memory
Listen to the story in 3.2 - check with the mother

5.3 Orientation
Ask the child what day it is.

Do you have any other information that will be of value to this assessment?

RECOMMENDATION

Mark with an X where applicable

FULL TIME CARE	PART TIME CARE	ABLE TO CARE FOR HIM/HER SELF	REFER FOR FURTHER ASSESSMENT

Opinion:

Name: Date:

Signature:

APPENDIX F: THE CAREGIVER'S CONSENT FORM

RESPONDENT NO: _____

University of Cape Town - Children's Institute
Care Dependency Grant Assessment Tool Study

CAREGIVERS CONSENT FORM

The Children's Institute wish to talk to parents and care-givers of children with illnesses and disabilities about the needs of their children and the additional problems they face in caring for them. It is hoped that this information shall be used by the government to improve the support given to care-givers and improve the access to the Care-Dependency Grant. However, this may take a long time.

Please note that this is not an application for the Care-dependency Grant, nor will there be immediate assistance from the government.

Everything you say will be kept private and confidential - your name shall not be recorded on the forms, nor given to anyone else. You do not have to answer any question if you do not wish to, and you may stop the interview at any time, without any prejudice, risk or loss of benefits.

I would like to ask you a few questions now for about one hour, and then I would like to come to your home and talk with you there again. If you agree to this, and have understood the information given, please could you sign below. The information on this paper is only so that I may come and visit you again – none of the information will appear on the question form.

Do you have any queries or concerns? We thank you for your assistance.

I _____ hereby freely and voluntarily give my permission to
(parent or caregiver's name)
be interviewed for this research. I understand the purpose of the study as explained to me. I understand that my answers to the questions will remain private. I understand that I may refuse to answer a specific question, and that I may request that we stop the interviews at any time.

Signature: _____ Address: _____

_____ Code: _____ Tel. No: _____

Date: _____ Place: _____

Thank you for agreeing to be part of this research.